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ABSTRACT

This resource manual lists and describes research projects, federally funded between 1989-91, that focus on children, youth, and families living with chronic illness and disabilities. The projects were supported by the National Institute on Disability and Rehabilitation Research, the Bureau of Maternal and Child Health, the Child and Adolescent Service System Program, and the National Institute of Mental Health. The project descriptions, generally one-half to one page in length, consist of directory-type information and a summary of project goals and activities. The project descriptions are organized into the following sections: infants; children; early childhood intervention; adolescents and young adults; transition and independence; social competence; family; parent focus; family centered, community based comprehensive services; cultural and geographical focus; respite care; behavioral focus; training and education; measurements, inventories and assessments; policy; health care expenses; chronic illness and disabilities, injury and trauma and rehabilitation; screening projects; Cooley's anemia, thalassemia; hemophilia and acquired immune deficiency syndrome; and home care, alternative care and technology dependence. (JDD)

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Compendium 1989-91:

A Research Resource Manual

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- ☐ Bureau of Maternal and Child Health
- ☐ Child and Adolescent Service System Program
- ☐ National Institute of Mental Health

INTRODUCTION

The Center for Children with Chronic Illness and Disability is a research and training center located at the University of Minnesota in Minneapolis. It is dedicated to the study and promotion of psychological and social well-being of children with chronic conditions and their families.

The staff is committed to fostering the physical, psychological and social development and competence of infants, children, and adolescents with chronic illness and disabilities. It has three primary goals: to train health, education and social service professionals; to conduct research; and to distribute information which promotes child competence and well-being to persons with disabilities and to their families, to professionals, and to policymakers at the local, state and national levels.

This resource manual lists and describes research projects, federally funded between 1989-91, which focus on children, youth, and families living with chronic illness and disabilities. The projects are supported by the National Institute on Disability and Rehabilitation Research, the Bureau of Maternal and Child Health, the Child and Adolescent Service System Program, and the National Institute of Mental Health. The purpose of compiling information from these four organizations is to create a single directory which focuses specifically on research being conducted about children, youth, and families living with chronic illness and disabilities and to promote collaboration between projects and agencies.

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TITLE: A Demonstration of Infant Mental Health Services

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PROJECT PERIOD: 10/90 – 09/93

SUMMARY:

The aim of this project is to extend principles and activities developed through the state level CASSP project in infant mental health to the local demonstration/research project. The local project will focus on the mental health service needs of children ages birth to three who are at risk for atypical psychosocial development/psychopathology due to parental/family conditions as identified by North Carolina's High Priority Infant Program and to evaluate the effectiveness of the interventions. To accomplish this goal, a two-pronged approach is designed. First, the local demonstration will include systems change strategies designed to: 1) increase early identification and referral of infants with signs of atypical psychosocial development and; 2) promote access to and utilization of community resources by their families. These strategies will be studied to determine effectiveness. Second, a clinical intervention is designed to ameliorate the delays/deviations in socio-emotional development of infants through the provision of family-focused, home-based intervention and case management services. These interventions will be studied to determine their impact on the child and family. A two county, rural mental health system in the Appalachian region of the state has been selected as the demonstration site. This project is expected to provide a unique opportunity to test the efficacy of infant mental health principles and practices which have been developing during the past decade. Information regarding strategies for increased network capabilities will also be available as a result of the project. The project site will become a "learning laboratory" to study those interventions found to be effective, and project results will be disseminated statewide.

TITLE: Adaptation of the FIM For Use with Infants and Children: Pediatric Evaluation of Disability Inventory

PRINCIPAL INVESTIGATOR:
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PROJECT PERIOD: 03/01/88 – 02/27/91

SUMMARY:

Children with chronic disabling disorders frequently are limited in their age-appropriate functional abilities. Much work has recently gone into the development of standardized uniform minimal systems of functional assessments for adults with disabilities and handicaps (e.g., the FUNCTIONAL INDEPENDENCE MEASURE). These instruments, however, are not useful for disabled children below age seven, and no other similar functional independence tool that is sensitive to developmental issues exists for infants and toddlers. The goal of this is to create a new instrument (PEDIATRIC EVALUATION OF DISABILITY INVENTORY) that is appropriate for infants, toddlers, and small children. Through the addition of developmentally relevant content, the items of the FIM will be revised. The test will then be standardized on a normative sample of infants and children and these data will be further analyzed to support the quality of the test in technical requirements such as reliability, validity, and precision. At the conclusion of this project, a diagnosis-independent method of measuring the functional status and progress of infants, toddlers, and small children will be available. Through the development of test and instruction manuals, training packages for professionals, and computer software to assist in scoring the test, wide dissemination and utilization of the Pediatric Evaluation of Disability Inventory will be achieved.

TITLE: Automated System for Monitoring Treatment Services for Children with Metabolic and Endocrine Disorders

PRINCIPAL INVESTIGATOR:
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PROJECT PERIOD: 10/01/89-09/30/90

SUMMARY:

The Vermont Newborn Screening Program has no organized system of followup to ensure that children with disorders diagnosed by screening are enrolled in treatment services or to monitor the quality of those services. The goal of this project is to have a system in place to ensure that the families of all children identified by the newborn screening program as having a disorder will have appropriate information and other sources available and will have all those services monitored in an appropriate manner.

TITLE: Developmental Consequences Of Extremely Low Birth Weight

PRINCIPAL INVESTIGATOR: Samuel Meisels, Ed.D.

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Development
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PHONE NUMBER: (313) 747–1084

PROJECT PERIOD: 07/01/89 – 06/30/92

SUMMARY:

This project focuses on infants who were born at severe biological and caregiving risk due to extreme prematurity (birth weight below 1250 grams) and concomitant long-term neonatal hospitalization. The project has two principal objectives. First, it follows the development of these extremely low birth weight (ELBW) infants over the course of their preschool years (i.e., ages 3 to 4½), studying their cognitive, psychosocial, and neurological growth. Second, it translates these findings into intervention strategies so that the developmental potential of ELBW infants born in the future can be significantly enhanced.

This work constitutes the second phase of a longitudinal study of ELBW infants. In the first phase, the infants (N = 56) were followed from birth, at term, and discharge, and then again at 4, 8, 14, and 19 months of age corrected for gestation. (A healthy, full-term group was also followed.) Initial results indicate that these infants are at high risk for developmental problems. At term, one-quarter had abnormal neurological exams, nearly 1 in 4 had periventricular leukomalacia, two-thirds had chronic lung disease, and nearly half were below the fifth percentile for weight. At 14 and 19 months significant proportions of the ELBW infants were at-risk on cognitive, psychosocial, and language measures.

Embodying an interdisciplinary approach that combines special education, clinical and developmental psychology, and pediatrics, this project is designed to make several major contributions. First, it represents a longitudinal research study of the preschool development of very high-risk infants at the "frontier" of neonatology that will help establish a descriptive baseline of cognitive, affective, and neurological development. And second, it will lead to the development of intervention plans and strategies that are specific to this very high-risk population and that can be utilized by other professionals committed to rehabilitation and intervention with extremely immature preterm infants.

TITLE: Impact of AIDS on Dependent Infants of the Court

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PROJECT PERIOD: 9/89 – 8/94

SUMMARY:

This five-year study is using a pooled cross-sectional and time series design to study the impact of the AIDS epidemic on services provided to infants who are dependents of the Juvenile Court of Los Angeles. A stratified random sample of infants at high risk for AIDS, infants who are HIV positive or have AIDS, and infants whose risks are unknown are being followed prospectively for 18 months to examine health care utilization, placements and infant characteristics. The research is exploring changes that occur in placement, foster care, and adoption as the number of HIV positive and high-risk infants continues to escalate and increased pressures are placed on service systems and agencies. The research also explores effects of the AIDS epidemic on the mental health, stress and coping of caseworkers who seek to arrange placements and adoption.

TITLE: Injury Recovery Study: Infants and Preschool Children

PRINCIPAL INVESTIGATOR: Wendy Coster, Ph.D.
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Boston, MA 02111

PHONE NUMBER: (617) 956–5031

PROJECT PERIOD: 01/01/88 – 12/31/92

SUMMARY:

Given the rapid development characteristics of the first five years of life, it is likely that trauma to the nervous and musculoskeletal systems may result in a clinical course unique to this age group. However, the long-term developmental, functional, and behavioral effects of injuries in infants and preschool children have not been clearly studied or described in the literature. The major goal of this project is to examine the injury recovery of children and families over a six-month period after hospital discharge. Contributing clinical sites are the Kiwanis Pediatric Trauma Institute at Floating Hospital for Infants and Children, Boston, MA and Baystate Medical Center, Springfield, MA. Physical and functional outcome measures include the Pediatric Evaluation of Disability Index, the Battelle Developmental Scales, and the Rand Child Health Questionnaire to examine health, activity level, and functional status. In addition to the physical and functional measures, child behavior and the psychosocial impact on the family are examined. Recruitment and data collection will continue in Year 4, with an increase in subjects expected following the addition of a second site (Baystate Medical Center). Results of this project will include: 1) the description and frequency of developmental, functional, and health outcomes after injury, 2) the description of child behaviors and the psychosocial impact on families, and 3) description of the differential profiles of injury problems across levels of injury severity, mechanisms, and types of injury, and subsequent patterns of recovery.

TITLE: NICU Care for VLBW Infants

PRINCIPAL INVESTIGATOR: Susan Leib, Ph.D.
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PROJECT PERIOD: 9/1/90 – 8/30/91

SUMMARY:

The overall purpose of this project is to conduct an investigation of the immediate and long-range effects of using Neonatal Individualized Developmental Care and Assessment Programming (NIDCAP) with preterm neonates at risk for chronic lung disease and poor neurological and developmental outcome who have been hospitalized in a Level III transport (outborn) NICU that uses standard conventional nursing for care of sick infants. NIDCAP procedures have shown promising results when implemented through a research model with at-risk infants in a Level III inborn NICU, using a primary nursing model of care (Als, et al., 1986) but have not been tested in other situations.

A repeated measures design will be used to determine the immediate and long-range effects of providing NIDCAP intervention. A total of 60 infants who meet study criteria will be randomly assigned to experimental and control groups. Experimental infants will receive observational assessments, every 7 days beginning by the 5th day of hospitalization, upon which written Individual Developmental Care Plans (IDCP) will be developed and charted by one of four trained nurses. In addition, each infant will be assigned for care to at least one study nurse across each three daily care shifts who will implement intervention and work with families in incorporating procedures into their interactions with their infant. Intervention will continue until the infant's discharge when it will be linked, through an individual Family Service Plan (IFSP), to the Neonatal Follow-Up Clinic and other community resources that may be needed by the family or infant following discharge. Planned transitions will be implemented by a designated case manager.

All experimental and control group infants will be followed longitudinally at 6, 12, and 24 months EDC (corrected age) through the Neonatal Follow-Up Clinic. Standard medical and developmental measures will be implemented during these visits. In addition, all families and their study infants will receive additional assessments at term (40 weeks corrected age), 2 weeks post-term (42 weeks corrected age), and 4 weeks post-term (44 weeks corrected age) and at each of the Follow-Up Clinic points. These data will be analyzed to determine the immediate and long-range effects of NIDCAP on medical outcome, infant behavioral outcome, and family outcome measures.

TITLE: Rehabilitative and Developmental Care of
the Very Low Birthweight (VLBW)
Newborn: Testing a Clinical Model

PRINCIPAL INVESTIGATOR: Heidelise Als, Ph.D.
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PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

The newborn with a birth weight of <1250g (<2$^{1}/_{2}$ lbs.) who requires mechanical ventilation is at very high risk for intraventricular hemorrhage (IVH) and for chronic lung disease (BPD), two potentially severely handicapping conditions jeopardizing survival and normal development. We hypothesize that caregiving in the Newborn Intensive Care Nursery (NICU), which is from day one on, consistently geared not only to the medical needs, but also to the individual newborn's developmental/behavioral needs and those of the infant's family reduces the initial danger of intraventricular bleeding, decreases respirator dependency, and improves significantly the developmental outcome.

We have successfully tested this hypothesis in a research model by utilizing an innovative developmental approach to individualized caregiving with a randomly selected experimental group and comparing outcome to a control group. We have used a structured detailed observation and written feedback procedure every 10th day, performed by trained developmental specialists in conjunction with developmental observational training of a group of primary bedside caregiving nurses. Outcome of the experimental group showed shorter stay on the ventilator, in supplemental oxygen, and on gavage feedings, lower incidence of intraventricular hemorrhage, reduced severity of bronchopulmonary dysplasia as well as much improved developmental outcome of the child and of the family. The second phase of the study has been to test a clinically integrated model of implementation by testing maintenance of quality control of the consistency of implementation of individualized care delivered by specially trained primary nursing teams through ongoing feedback and support by the developmentally trained clinical nurse specialist (CNS) in the NICU. Twenty VLBW respirator-dependent infants meeting the study criteria were randomly assigned in the course of a 22-month intake period to trained nursing teams supported by the developmental CNS. The outcome of these infants and their families is compared to 20 control infants' outcomes. Current analysis of the data will show whether their outcome is improved, as was the case in phase I of the research. Should this be so, we will have the basis of a cost-effective model which can be instituted and transmitted to other institutions via the training program we have developed.

TITLE: Southeast Asian Developmental Project

PRINCIPAL INVESTIGATOR: James O. Cleveland, Ed.D.
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PROJECT PERIOD: 10/01/89 – 09/30/92

SUMMARY:

This project will develop a model program to reduce the ethnocultural barriers and enhance the availability and utilization of genetic and other maternal and child health services for the Southeast Asian refugee populations in San Diego County. The project will have an impact on this target population with respect to increasing the understanding, acceptance, and utilization of Western health care services. The project will enhance the understanding and sensitivity level of primary and secondary health care providers to the cultural practices, attitudes, and health care needs of this target population.

TITLE: A Longitudinal Study of Children With Chronic Illness and Disability

PRINCIPAL INVESTIGATOR: Robert Wm. Blum, M.D., Ph.D.,
Joan Patterson, Ph.D.
Center for Children with Chronic Illness and Disability
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PHONE NUMBER: (612) 626–4032

PROJECT PERIOD: 1990 – 1994

SUMMARY:

1. What are the individual child (e.g., personality, developmental), disease-specific, familial (e.g., composition, interactive styles) and environmental (e.g., school, neighborhood) factors associated with resilience and optimal psychosocial outcomes for children and youth with chronic illness and disability?

2. What are the interactive effects between the key predictor variables of optimal psychosocial outcomes?

3. How do the predictive variables and interactions change over time as the child matures, the family and/or environments change, and/or the condition itself fluctuates?

Two age cohorts of children (birth–2 years and 8–10 years) who are newly diagnosed with a chronic illness or disability (e.g., cystic fibrosis, spina bifida, mental retardation) and their families will be followed for five years. The goal of the study is to identify those individual, familial, and environmental risk and protective factors associated with competence and well-being. Conditions selected will allow examination of the differential impact of visible vs. invisible conditions, cognitive vs. physical impairment, and progressive vs. uncertain or stable illness course on child and family outcomes. In addition, the study will explore how these factors interact and change over time as the child matures, the condition fluctuates, the family changes, and/or the environmental context changes. Identification of the risk and protective factors associated with competent child and family functioning will lead to demonstration programs and intervention studies designed to promote resilience in children with disabilities and their families, the focus of the study is on the psychosocial impact of chronic illness and not specific conditions.

Cooperation is being solicited from all hospitals and pediatricians treating children in Minnesota's seven-county Metro area and Washington's three-county Metro area and procedures for identifying subjects are being established. Sample selection and time of diagnosis are within six months from time of diagnosis. The first draft of the entire research protocol has been developed and is under review by investigators. Human subjects approval has been received. Piloting of research protocol with families will take place in October and data collection will commence in November of 1990.

TITLE:	A Longitudinal Study of Medically Fragile Children
PRINCIPAL INVESTIGATOR:	Barbara Leonard, Ph.D. Center for Children with Chronic Illness and Disability Box 721 UMHC Minneapolis, MN 55455
PHONE NUMBER:	(612) 626–4032
PROJECT PERIOD:	1990 – 1994

SUMMARY:

1. What are the social and emotional consequence to families who provide home care to children who are technology-dependent?
2. In families where there appears to be the capability to manage the demands of home care successfully, what factors contribute to the capability?

Based upon the Longitudinal Study of Children with Chronic Illness and Disability, the sample will include some children dependent upon medical technology. This subsample of children and their families will be followed as part of Study #1. For all of the children in Study #1, we will continue to follow them, if and when they are placed in alternative settings, examining factors that give rise to these out-of-home placements, costs associated with care in whatever setting, length of time in alternative settings, and impact of setting on child and family outcomes.

TITLE: Adaptation of the FIM For Use with Infants and Children: Pediatric Evaluation of Disability Inventory

PRINCIPAL INVESTIGATOR:
Stephen Haley, Ph.D.
Department of Rehabilitation Medicine
Tufts University School of Medicine
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750 Washington St
#75K-R
Boston, MA 02111

PHONE NUMBER: (617) 956-5031

PROJECT PERIOD: 03/01/88 – 02/27/91

SUMMARY:

Children with chronic disabling disorders frequently are limited in their age-appropriate functional abilities. Much work has recently gone into the development of standardized uniform minimal systems of functional assessments for adults with disabilities and handicaps (e.g., the FUNCTIONAL INDEPENDENCE MEASURE). These instruments, however, are not useful for disabled children below age seven, and no other similar functional independence tool that is sensitive to developmental issues exists for infants and toddlers. The goal of this is to create a new instrument (PEDIATRIC EVALUATION OF DISABILITY INVENTORY) that is appropriate for infants, toddlers, and small children. Through the addition of developmentally relevant content, the items of the FIM will be revised. The test will then be standardized on a normative sample of infants and children and these data will be further analyzed to support the quality of the test in technical requirements such as reliability, validity, and precision. At the conclusion of this project, a diagnosis-independent method of measuring the functional status and progress of infants, toddlers, and small children will be available. Through the development of test and instruction manuals, training packages for professionals, and computer software to assist in scoring the test, wide dissemination and utilization of the Pediatric Evaluation of Disability Inventory will be achieved.

TITLE: Assessment and Treatment of Abuse in Handicapped Children

PRINCIPAL INVESTIGATOR: Robert T. Ammerman, Ph.D.
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Children
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PHONE NUMBER: (412) 683–5960

PROJECT PERIOD: 09/01/88 – 08/31/90

SUMMARY:

The objectives of this study were to: a) develop a comprehensive assessment strategy for examining incidence and characteristics of abuse and neglect in psychiatrically referred multihandicapped children and their families, and b) implement and evaluate a comprehensive behavioral treatment to remediate multiple problem areas in parents who maltreat their children. In Phase I, we examined the incidence of maltreatment in 150 consecutive admissions of multihandicapped children and adolescents to a psychiatric hospital. Nonmaltreated children and their families served as a control group for maltreating families in Phases 2 and 3. Phase 2 consisted of a broad assessment of psychosocial functioning of children in families, including measures of psychopathology, parenting practices, anger responsivity, child management skills, and child abuse potential. Phase 3 involved a 10-minute play interaction between mother and child that was videotaped and will be retrospectively rated for interaction patterns reflecting abusive or neglectful parenting styles. Finally, Phase 4 comprised the implementation of a Comprehensive Behavioral Treatment (CBT) to parents engaging in abuse and/or neglect. CBT is a 12-week skills-based intervention emphasizing: 1) child management skills, 2) stress reduction, 3) anger control training, and 4) problem-solving training. The goals of treatment are decreased risk for further abuse and/or neglect and enhanced parenting effectiveness. Systematic follow-up probes were conducted 6 to 12 months post-treatment to evaluate maintenance of treatment effects. Furthermore, periodic "booster" sessions were utilized on a prospective basis to prevent behavioral decrements.

TITLE: Cognitive and Communication Development in Children with Severe Disabilities

PRINCIPAL INVESTIGATOR: Harvey Mar, Ph.D.
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428 West 59th St
New York, NY 10019

PHONE NUMBER: (212) 523–6230

PROJECT PERIOD: 09/01/89 – 08/31/92

SUMMARY:

This field-initiated research and demonstration project focuses on the development of communication and cognition in children with severe disabilities. Several studies are being conducted that: (1) examine parallels in cognitive and communication behaviors when intellectual functioning is severely impaired; (2) seek to identify prerequisite cognitive abilities associated with communicative competence; (3) task analyze the cognitive requirements for using various communication-training strategies and augmentative devices; and (4) examine ways to adapt communication technology to meet the needs of children with severe intellectual and communication impairment. The research is being conducted with 140 students, ages 3 to 15, from public schools in New York City. All of these students have been determined to have multiple disabilities, including severe communication impairment and moderate, severe, or profound mental retardation. Data are obtained through assessments, observations, structured interactions, parent and teacher interviews, and record reviews of each student on periodic bases. In addition to the research studies, this project is developing protocols to assess cognitive, communication, and daily-living behaviors; software for coding and monitoring students' communication behaviors for purposes of planning interventions; and a "feature-matching" software program to relate a student's level and range of communicative and cognitive skills to appropriate intervention strategies and/or devices.

TITLE: Fostering Individualized Mental Health Care: A Study

PRINCIPAL INVESTIGATOR:
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PROJECT PERIOD: 10/90 – 09/93

SUMMARY:

This project demonstrates both a local and national need for data on the effectiveness and efficacy of programs aimed at stabilizing placements for foster children at high risk for serious emotional disturbance (SED), largely due to emotional neglect and physical or sexual abuse. The purpose of this study is threefold: 1) to establish an individualized system of mental health care for foster children who are at risk for serious emotional disturbance; 2) using randomly selected pools of children, who are randomly assigned to two treatment groups, to conduct a controlled analysis of the efficacy and effectiveness of the two treatment systems (i.e. Foster Individualized Assistance Program (FIAP) utilizing the Mental Health Intervention Specialist as therapeutic case manager and home preservationist and Standard Treatment) in stabilizing the placements and improving the emotional/behavioral adjustment of the foster children in both groups; and 3) to utilize the results of the study and the FIAP's effects to confront a children's mental health system that is severely overtaxed by increases in the number of foster children needing mental health services, by addressing and adjusting a major part of Florida's five-year mental health state plan for children, and by enhancing the achievement of Florida's CASSP goals (e.g., family participation and individualized systems of care) for severely emotionally disturbed (SED) children, through replication and dissemination of positive results throughout the state.

TITLE: Injury Recovery Study: Infants and Preschool Children

PRINCIPAL INVESTIGATOR: Wendy Coster, Ph.D.
Department of Rehabilitation Medicine
Tufts University School of Medicine
New England Medical Center
750 Washington St
#75K–R
Boston, MA 02111

PHONE NUMBER: (617) 956–5031

PROJECT PERIOD: 01/01/88 – 12/31/92

SUMMARY:

Given the rapid development characteristics of the first five years of life, it is likely that trauma to the nervous and musculoskeletal systems may result in a clinical course unique to this age group. However, the long-term developmental, functional, and behavioral effects of injuries in infants and preschool children have not been clearly studied or described in the literature. The major goal of this project is to examine the injury recovery of children and families over a six-month period after hospital discharge. Contributing clinical sites are the Kiwanis Pediatric Trauma Institute at Floating Hospital for Infants and Children, Boston, MA and Baystate Medical Center, Springfield, MA. Physical and functional outcome measures include the Pediatric Evaluation of Disability Index, the Battelle Developmental Scales, and the Rand Child Health Questionnaire to examine health, activity level, and functional status. In addition to the physical and functional measures, child behavior and the psychosocial impact on the family are examined. Recruitment and data collection will continue in Year 4, with an increase in subjects expected following the addition of a second site (Baystate Medical Center). Results of this project will include: 1) the description and frequency of developmental, functional, and health outcomes after injury, 2) the description of child behaviors and the psychosocial impact on families, and 3) description of the differential profiles of injury problems across levels of injury severity, mechanisms, and types of injury, and subsequent patterns of recovery.

TITLE:	Mental Disorders in Pediatric Care Settings
PRINCIPAL INVESTIGATOR:	Emily Harris, M.D. Children's Hospital at Stanford 520 San Hill Road, Box 17 Palo Alto, CA 94304
PHONE NUMBER:	(415) 853-3302
PROJECT PERIOD:	09/89 – 08/94

SUMMARY:

Dr. Harris is a child psychiatrist who is using this five-year scientist development award to further the growth of her research skills in the area of mental health services for children. In addition to formal coursework in social epidemiology, clinical data base management, and the economics of health care, Dr. Harris is undertaking a number of research studies on issues related to clinical detection and management of mental disorders in tertiary care pediatric settings. The research also involves a study of the impact of a major reorganization and restructuring of the child psychiatry consultation service at the Stanford University Medical Center. Dr. Harris' career goal is to be a leader in scientific research at the interface of pediatrics and child psychiatry while also continuing to be active in clinical care and teaching.

TITLE:	National Clearinghouse on Family Support and Children's Mental Health
PRINCIPAL INVESTIGATOR:	Marilyn McManus, J.D., M.S.W. Regional Research Institute for Human Services Portland State University P.O. Box 751 Portland, OR 97207–0751
PHONE NUMBER:	(503) 725–4040
PROJECT PERIOD:	10/01/89 – 09/30/94

SUMMARY:

The National Clearinghouse on Family Support and Children's Mental Health is the first clearinghouse designed to serve families of children with serious emotional disorders as well as professionals, policy-makers and other interested persons. It includes a national toll-free telephone service (800–628-1696), a computerized data bank, a series of fact sheets on issues pertaining to children who have emotional disabilities and their families, a state-by-state resource file, and the addition of a family resource coordinator to the Center's staff.

Available fact sheets address the following topics: children's mental, emotional, and behavioral disabilities; resources (books, journals, newsletters, and films) addressing children's mental health issues; starting parent/family support groups; financing; early intervention services; and descriptions of specific children's emotional disabilities including childhood depression, attention deficit hyperactivity disorder, and childhood schizophrenia.

TITLE: North Idaho CASSP: A Rural System of Care Model

PRINCIPAL INVESTIGATOR: Jody Lubrecht, Ph.D.
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PROJECT PERIOD: 10/90 – 09/93

SUMMARY:

Through a local demonstration model, this project will develop and evaluate a Region-wide pilot system of highly individualized and rurally-compatible alternatives to residential treatment by implementing innovative service components, including Classroom Companion and Crisis and Respite Companion Services, Treatment Family Placement Capacity, Family-Centered Hospitalization Capacity, and Wraparound Services Funding Capacity throughout the Region in order to enhance and expand upon existing Family-Centered Assessment, Family Case Management, Intensive Family Therapy and Support Services. As fewer and fewer Region I children require out-of-school and out-of-community placement, state dollars will gradually be diverted to Region I from existing residential treatment contracts for the ongoing funding of services. The target population for this demonstration will include all severely emotionally and severely behaviorally disturbed children from Region I currently out-of-school and out-of-community placement or at imminent risk for such placement (as identified via the routine provision of Departmental services to child protection, child mental health and juvenile justice services populations and via collaborative classroom projects with selected Region school districts). The implementation of a comprehensive rural system of care in Region I, and the hypothesis-based investigation of the effectiveness of such a system as compared with Region III's traditional day treatment and out-of-community residential treatment services, would allow Idaho to demonstrate to rurally-based children's services agencies nationwide, the effectiveness of individualized, para-professionally-staffed components of care to expand the range of services available to severely disturbed children and their families.

TITLE: Nutrition Care for the Child with Special Health Care Needs

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Birmingham, AL 35294

PHONE NUMBER: (205) 934-0803

PROJECT PERIOD: 09/01/88 – 06/30/93

SUMMARY:

Nutrition for the Child with Special Health Care Needs is an intensive, one-week course for multidisciplinary team members concerned the nutritional needs of this population. It is taught at two different sites, with an overall goal of improving nutrition awareness and services for the child with special health care needs.

TITLE:	OE Grant: Intensive Behavioral Treatment of Young Developmentally Delayed Children
PRINCIPAL INVESTIGATOR:	Tristram Smith University of California—Los Angeles Department of Psychology 405 Hilgard Avenue Los Angeles, CA 90024–1563
PHONE NUMBER:	(213) 835–2319
PROJECT PERIOD:	03/15/88 – 03/15/91

SUMMARY:

The present investigation is intended to enhance the intellectual, educational and social skills of young, developmentally delayed children so that they can take better advantage of the educational opportunities provided for them in the public schools. The investigation is modeled after a recently completed and lasting study (Lovaas, 1987) showing major improvement in young autistic children. For example, 9 of 19 intensively treated children were able to enter normal classes in the public school system. The present investigation is intended to test the generality of these findings on a non-autistic population and incorporates certain methodological improvements. The program is community-based: trained student-teachers work with the children in the children's homes, assisted by the children's peers, parents, and teachers who are also taught how to provide the treatment. The children received 30 hours or more per week of 1:1 individualized treatment, lasting for 2 or more years. Intervention addresses a variety of interrelated intellectual, educational, and social behaviors, and does contain steps to help children transfer from the treatment program to the public schools.

An intensively treated experimental group (N = 20) will be compared to a control group (N = 20) comprised of children who are similar at intake. Assignment of subjects to groups is made by investigators independent of the study, using a matched-pair procedure. The control group receives a three-month parent training course from the project and then is referred to services available in the community for developmentally disabled children. A large variety of pre- and post-treatment measures are employed, administered by staff who are blind as to group assignment.

To date, we have enrolled in treatment 26 subjects, diagnosed as having mild to moderate mental retardation of unknown etiology. The mean IQ of the subjects at intake is 51 (range 36 to 75). CA at intake is 29 months (range 18 to 42 months). We plan to enroll the remaining 14 subjects needed by November 1, 1990. Preliminary assessments of outcome are consistent with our previous findings. The experimental group shows an increase of about 20 IQ points while the control group shows essentially no change. So far, six of the thirteen experimental group children are being integrated into normal classes. Thus, intensive treatment in the experimental group appears to be associated with a clinically meaningful improvement in children's intellectual, educational, and social skills.

TITLE: Pediatric Provision of Mental Health Services

PRINCIPAL INVESTIGATOR: Philip J. Leaf, Ph.D.
Department of Psychiatry
Yale University
350 Congress Avenue
New Haven, CT 06519

PHONE NUMBER: (203) 785–5551

PROJECT PERIOD: 02/87 – 01/92

SUMMARY:

Previous research suggests that pediatricians often fail to identify psychosocial problems in their patients and make limited use of referrals to mental health specialists. In a five-year longitudinal study of a stratified random sample of children being seen by pediatricians in south-central Connecticut, Dr. Leaf is studying the extent to which pediatricians function as a part of the mental health service system for children ages four through eight. The goals of the study are to determine: (1) the extent to which pediatricians provide or refer children for mental health related treatment; (2) the extent to which physician, patient, and family characteristics influence detection of psychosocial problems; (3) the outcomes associated with the identification of these problems in children.

TITLE: Physical Functioning and Motor Outcomes of Injured Children and Adolescents

PRINCIPAL INVESTIGATOR: Stephen Haley, Ph.D.
Department of Rehabilitation Medicine
Tufts University School of Medicine
New England Medical Center
750 Washington Str
#75K–R
Boston, MA 02111

PHONE NUMBER: (617) 956–5031

PROJECT PERIOD: 01/01/88 – 12/31/92

SUMMARY:

Children with traumatic injuries frequently exhibit residual physical and functional motor deficits. The major goal of this project is to examine the physical functioning and motor recovery of children and adolescents after a traumatic injury. Contributing clinical sites are the Kiwanis Pediatric Trauma Institute at Floating Hospital for Infants and Children, Boston, MA and Baystate Medical Center, Springfield, MA. Physical and functional motor outcomes are being examined at hospital discharge, one month, three months, and six months after hospital discharge. Pre-injury data (retrospective from parents) includes the social competence and activity scale of the Child Behavior Checklists and the physical health section of the Rand Child Health Scale. Measurements taken at hospital discharge are the short form of the Scales of Independent Behavior and the Fine Motor Section of the Bruininks-Oseretsky Test of Motor Proficiency. General measures of physical function and activity taken at one, three, and six months are the physical scales of the Child Health Scale. More specific and detailed measures taken at one and six months post-discharge on those children who are able to return for a follow-up visit are the Scales of Independent Behavior, the gross and fine motor sections of the Bruininks-Oseretsky Test of Motor Proficiency, and the social competence and activity scales of the Child Behavior Checklist. Outcomes will include: 1) the description and frequency of motor and functional outcomes after injury, and 2) the differential pattern of injury related problems across severity levels of trauma.

TITLE: Physician Interview Style and Detection of Child Abuse

PRINCIPAL INVESTIGATOR: Lawrence Wissow, M.D., M.P.H.
Johns Hopkins Hospital
600 N. Wolfe St, CMSC 136
Baltimore, MD 21205

PHONE NUMBER: (301) 955–5437

PROJECT PERIOD: 09/89 – 08/93

SUMMARY:

This research is concerned with factors affecting the ability of pediatricians to detect and manage signs of child abuse and neglect. More specifically, the researchers are testing whether the interviewing styles of pediatricians are related to their responses to cases in which abuse or neglect may be suspected, and to their use of social work referral services for families at risk for maltreatment. The research team will assess responses of pediatric residents in a large, inner city hospital to clinical vignettes of maltreatment cases as well as review all resident referrals to social work for abuse or neglect. The study is also assessing the residents' interview styles in real-life encounters with clients, sensitivity to parental psychosocial distress, knowledge of child maltreatment, and definitions of what constitutes serious maltreatment.

TITLE: Preschooler's Behavior Problems: Pediatric Provision of Mental Health Services

PRINCIPAL INVESTIGATOR: John Lavigne, Ph.D.
Children's Memorial Hospital
2300 Children's Plaza
Chicago, IL 60614

PHONE NUMBER: (312) 880–4877

PROJECT PERIOD: 09/89 – 08/91

SUMMARY:

This project examines the ability of pediatricians to identify behavior problems in preschool children, pediatrician patterns of referral to mental health specialists, and use of health services by young children with behavior problems. Four thousand children ages 2 to 5 years are being screened in a well-established pediatric research network composed of over 40 physicians from a variety of practices and settings. All children screening positive and a random subset with negative screens are assessed in more detail with a multi-method, multi-informant behavioral and developmental evaluation. These assessments are then compared with pediatrician evaluations of these children in order to identify factors affecting provider recognition and referral of mental health problems.

TITLE:	Psychosocial and Family Outcomes of Injured Children and Adolescents
PRINCIPAL INVESTIGATOR:	Donald Wertlieb, Ph.D. Department of Rehabilitation Medicine Tufts University School of Medicine New England Medical Center 750 Washington St #75K–R Boston, MA 02111
PHONE NUMBER:	(617) 956–5031
PROJECT PERIOD:	01/01/88 – 12/31/92

SUMMARY:

Rehabilitation services for childhood trauma include a broad array of child and family interventions to enhance the recovery process. Rehabilitation programs are not complete, nor are they likely to be effective if the negative psychosocial impact of injury on children and families is not adequately addressed. The major goal of this project is to understand the nature and extent of child and family psychosocial problems after traumatic injury. Contributing clinical sites are the Kiwanis Pediatric Trauma Institute at Floating Hospital for Infants and Children, Boston, MA. A battery of measures assess child and family psychosocial status as well as school reintegration status at one month and again at six month post discharge. The measures include the Child Behavior Checklist, the Impact of Family Scale and School Reintegration Checklist. At the six-month follow-up, an additional measure is introduced with a Teacher Questionnaire to assess school behavior and academic performance. Outcomes of this project will include: 1) the description and frequency of child behavior problems, family disruption and stress, and school reintegration problems after injury, 2) the differential pattern of injury related psychosocial and school problems across varying trauma severity levels, and 3) the extent of recovery of behavior, psychosocial and school problems for injured children over a six-month periods, and how psychosocial factors relate to injury recovery.

TITLE:	Psychosocial Determinants of Children's Primary Care Use
PRINCIPAL INVESTIGATOR:	Anne W. Riley, R.N., Ph.D. Johns Hopkins University Kennedy Institute 707 North Broadway, Room 205 Baltimore, MD 21205
PHONE NUMBER:	(301) 522–9455
PROJECT PERIOD:	08/88 – 06/91

SUMMARY:

To identify the mental health determinants of pediatric medical care utilization, Dr. Riley is conducting a two-year, prospective study of children (ages 5–13) and their parents recruited from low, medium, and high users of medical care services in a large, suburban health maintenance organization. Baseline retrospective data are being collected on medical care utilization and morbidity. Prospective data are being collected on: children's health and behavioral status, parents' mental health status and learned ways of responding to symptoms and distress, stressful life events, and family functioning. The study results are expected to provide the biopsychosocial theoretical structure required to determine the role of modifiable psychosocial factors in appropriate and inappropriate pediatric care seeking.

TITLE: RTC in Rehabilitation and Childhood Trauma Project: National Pediatric Trauma Registry

PRINCIPAL INVESTIGATOR:
Carla Di Scala, Ph.D.
Department of Rehabilitation Medicine
Tufts University School of Medicine
New England Medical Center
750 Washington St
#75K–R
Boston, MA 02111

PHONE NUMBER: (617) 956–5031

PROJECT PERIOD: 01/01/88 – 12/31/92

SUMMARY:

The National Pediatric Trauma Registry (NPTR) is a collection of information about unintentional injuries occurring in children and young adults admitted to trauma centers for treatment. Started in April 1985, it currently includes about 22,000 cases of injuries and is increasing at a rate of approximately 6,000 cases a year.

The Registry is supported by the American Pediatric Surgical Association (APSAP) and data to the Registry are contributed by 50 trauma centers of children's hospitals on a voluntary basis.

The data collected in the Registry includes demographics, detailed description of the injury event, management of the victim at the scene, severity at the time of admission to the trauma center, management at the trauma center, discharge status, functional assessment at discharge, diagnoses and procedures performed.

Measures of severity include Abbreviated Injury Scale (AIS), Injury Severity Score (ISS), Glasgow Coma Scale (GCS), and Pediatric Trauma Score (PTS). Functions at discharge are assessed by a checklist of daily activities as well as by the Functional Independence Measure (FIM), where applicable. Diagnosis and procedure are recorded using the ICD-9 CM codes. The external causes of injury and accident scene are recorded using E-codes.

The Registry encompasses many aspects of pediatric trauma. It has been used to document pediatric injury outcome and to assess acute and rehabilitative treatment efficacy. Work is currently in progress to quantify morbidity resulting from injuries and to identify predictions of long-term outcomes.

TITLE: Social Competency Assessment

PRINCIPAL INVESTIGATOR: Scott McConnell, Ph.D.
Center for Children with Chronic
Illness and Disability
Box 721 UMHC
Minneapolis, MN 55455

PHONE NUMBER: (612) 626–4032

PROJECT PERIOD: 1990 – 1994

SUMMARY:

1. What are the age/developmental, social/contextual, family, and condition-related variables associated with social competence among children and youth with disabilities?
2. How does social competency vary among various environments within which the child with disabilities interacts?
3. What are the factors associated with social competence in various settings?

The goal of this study is to identify how competence is manifested in various environments and how those environments support or inhibit the competence of children with chronic illness or disability. Social competence, as one of the marker variables of children's psychosocial development in the above-mentioned longitudinal study, will be assessed in multiple settings—home, school, neighborhood, and hospital. Differences in social competence by setting will be examined and developmental, social, family, and condition-related predictors of competence will be identified.

This study is an integral part of Study #1 and, hence, planning has been concurrent. Research instruments have been selected and will be piloted as pat of the entire research protocol for Study #1. A subsample of #1 will be drawn after enrollment is completed (Year 3) so that assessment of social competence in one additional setting can be carried out.

TITLE: Community-Based Medical/Educational Program

PRINCIPAL INVESTIGATOR: Mary Ellen Caffrey, Ph.D.
Ken-Crest Centers
One Plymouth Meeting, Room 620
Plymouth Meeting, PA 19462

PHONE NUMBER: (215) 844–4260

PROJECT PERIOD: 10/01/89 – 09/30/94

SUMMARY:

This project will add pediatric and nursing components to an existing early intervention program so that it can accommodate technology-dependent children. The center will use a coordinated approach to provide medical services, under which an individual pediatric service plan (IPSP) will be developed for each child. Target children will receive daily developmental programming which will include training in cognitive, motor, social, language, and self-help development. The project also will feature a parent training and advocacy component that aims to teach parents how to deal more effectively with their children's special medical and developmental needs.

TITLE: Early Identification of Hearing-Impaired Children

PRINCIPAL INVESTIGATOR: Karl R. White, M.D.
Utah State University
UMC 6580
Logan, UT 94322

PHONE NUMBER: (801) 750–2003

PROJECT PERIOD: 06/01/89 – 05/31/92

SUMMARY:

Using the materials and expertise gained over the last 10 years in operating a birth certificate-based screening program for hearing impaired children in Utah, this project will implement and evaluate the cost-efficiency of such programs in two additional states (Oregon and Iowa). The objective of the project is that over the 36-month period of the project, participating states will increase by 50 percent the number of hearing-impaired children identified by 12 months of age.

TITLE: Early Intervention Collaborative Study: Preschool Phase

PRINCIPAL INVESTIGATOR: Jack P. Shonkoff, M.D.
University of Massachusetts Medical School
Department of Pediatrics
55 Lake Avenue North
Worcester, MA 01655

PHONE NUMBER: (508) 856–3028

PROJECT PERIOD: 04/01/89 – 12/31/92

SUMMARY:

This 4-year study is a continuation (Phase II) of a nonexperimental longitudinal investigation of the development of 217 children with disabilities and their families after their transition from early intervention programs to preschool settings. The long-term objectives of this study are to examine the stability of effects of early intervention services (utilizing comprehensive data collected during Phase I) and to identify the predictors of subsequent child competence and family adaptation during the preschool period.

TITLE: Evaluation of Interventions in Childhood Brain Injuries

PRINCIPAL INVESTIGATOR: Martha A. Foster, Ph.D.
Georgia State University
Department of Psychology
University Plaza
Atlanta, Georgia 30303

PHONE NUMBER: (404) 651–2283

PROJECT PERIOD: 09/90 – 8/93

SUMMARY:

The goal of this research demonstration is to determine whether child-focused or child- and family-focused treatment is more effective in promoting positive outcomes in children with closed head injuries (CHI). The research will include children ages 6 to 15 who have recently sustained a moderate to severe CHI and who are at significant risk of developing chronic emotional and behavioral problems. Three study groups include a wait-list control, an experimental group with child-focused therapy, and an experimental group with both child- and family-focused therapy. Children in both experimental groups will complete at least 16 weeks of child-focused psychological treatment in a Transition Classroom Program at Georgia State; children in the second experimental group will participate with their families in at least 16 Structural Family Therapy sessions.

TITLE: Facilitation of Primary Care Physician Participation in Preventive Health Care

PRINCIPAL INVESTIGATOR: Gail Breakey, R.N., M.P.H.
Hawaii Family Stress Center
2919 Kapiolani Boulevard, Suite 30
Honolulu, HI 96826

PHONE NUMBER: (808) 732–0000

PROJECT PERIOD: 10/01/86 – 09/30/90

SUMMARY:

This project aims to reduce the incidence of poor health characteristics among low-income, culturally diverse populations by promoting the involvement of primary care physicians (pediatricians) in early screening and intervention. Project goals include increasing the level of preventive health care for underserved children, reducing the severity of psychosocial problems, increasing physicians' sense of involvement as part of a team in providing services to project children and their families, and demonstrating a practical process for accomplishing these goals which can be replicated across the nation.

TITLE: Improving Memory of EMR Children

PRINCIPAL INVESTIGATOR: Hilary Horn Ratner, Ph.D.
Wayne State University
Psychology Department
71 West Warren
Detroit, MI 48202

PHONE NUMBER: (313) 577–5244

PROJECT PERIOD: 07/01/87 – 10/31/89

SUMMARY:

This study's objective is to develop, for educable mentally retarded (EMR) children, instructional strategies that are embedded in a social context and will enhance children's memory performance across time and situation. Specifically, the project tests the use of a 12-week training program in which the subject children's memory skills will be exercised and developed through the use of demand conditions and self-generated memory strategies. With the accomplishment of this objective, it is hoped that EMR children will reach a more nearly normal level of functioning in society.

TITLE: Maternal and Child Health Cooperative Agreement

PRINCIPAL INVESTIGATOR:
Linda Gerson, Ph.D.
Regional Center for Infants and Young Children
11710 Hunters Lane
Rockville, MD 20852

PHONE NUMBER: (301) 984–4444

PROJECT PERIOD: 10/01/86 – 09/30/91

SUMMARY:

The goal of this project is to develop and implement comprehensive and family-centered approaches to early identification, assessment, and treatment of infants and young children who are at risk for or suffering from emotional and/or regulatory difficulties. To this end, the Regional Center for Infants and Young Children plans to: (1) Monitor types of families and children referred to and receiving services from an agency specializing in the early detection of emotional disorders or potential risk; (2) develop principles and technology to identify infants and young children/families at risk for psychosocial and developmental difficulties; (3) develop comprehensive, family-centered approaches to assessment and diagnosis; (4) develop prevention-oriented, family-centered approaches to intervention; (5) develop and disseminate technical assistance and training approaches; (6) engage State and local maternal and child health (MCH) agencies in the project; and (7) access multiple financial resources to support its efforts.

TITLE: Nutrition Project for Children with Special Needs

PRINCIPAL INVESTIGATOR:
Daniel J. Gossert, A.C.S.W., M.P.H.
Colorado Department of Health
Family and Community Health Services
4210 East 11th Avenue
Denver, CO 80220

PHONE NUMBER: (303) 331–8359

PROJECT PERIOD: 10/01/88 – 09/30/91

SUMMARY:

An estimated 73 percent of the children in the Colorado Handicapped Children's Program have nutritional problems which may interfere with optimal growth and development and may increase the debilitating effects of their handicap or chronic illness. Prior to the implementation of the Nutrition Project for Children with Special Needs, there was no systematic way to find and offer nutrition intervention to children in the Colorado Handicapped Children's Program. The goal of the Nutrition Project for Children with Special Needs is to develop a replicable nutrition intervention system to reduce or prevent the debilitating effects of poor nutrition in children with handicapping conditions and chronic illness.

TITLE: Nutrition Surveillance, Intervention, and Training in the Early Intervention Population

PRINCIPAL INVESTIGATOR: Cynthia Taft Bayerl, R.D., M.S.
Jacque Ries, R.D., M.P.H.
Massachusetts Department of Public Health
and the Shriver Center
150 Tremont Street, Fourth Floor
Boston, MA 02111

PHONE NUMBER: (617) 727–5822 or 642–0226

PROJECT PERIOD: 10/01/88 – 09/30/91

SUMMARY:

The goals of this project are to: (1) Collaborate with early intervention (EI) programs in the New England region to establish an ongoing nutrition service system that provides screening and assessment; (2) establish a central reporting system to determine the nutritional status of the nutritionally at-risk population; and (3) establish a system of screening, referral, and assessment to identify children in the EI program who are at nutritional risk. A permanent training program and resource manual will be incorporated into the orientation program for all EI providers and professionals.

TITLE: Physician Interview Style and Detection of Child Abuse

PRINCIPAL INVESTIGATOR: Lawrence Wissow, M.D., M.P.H.
Johns Hopkins Hospital
600 N. Wolfe St, CMSC 136
Baltimore, MD 21205

PHONE NUMBER: (301) 955–5437

PROJECT PERIOD: 09/89 – 08/93

SUMMARY:

This research is concerned with factors affecting the ability of pediatricians to detect and manage signs of child abuse and neglect. More specifically, the researchers are testing whether the interviewing styles of pediatricians are related to their responses to cases in which abuse or neglect may be suspected, and to their use of social work referral services for families at risk for maltreatment. The research team will assess responses of pediatric residents in a large, inner city hospital to clinical vignettes of maltreatment cases as well as review all resident referrals to social work for abuse or neglect. The study is also assessing the residents' interview styles in real-life encounters with clients, sensitivity to parental psychosocial distress, knowledge of child maltreatment, and definitions of what constitutes serious maltreatment.

TITLE: Project AIMS

PRINCIPAL INVESTIGATOR: Susan Partridge, M.S.W., Ph.D.
University of Southern Maine
Human Services Development Institute
96 Falmouth Street
Portland, ME 04102

PHONE NUMBER: (207) 780–4430

PROJECT PERIOD: 10/01/86 – 09/30/91

SUMMARY:

Project AIMS works to strengthen the capacity of Maine's service system (including P.L. 99-457 efforts) to meet the emotional health needs of young children (birth to 5 years old) and their families. The project objectives are to: (1) Establish a multidisciplinary network of project associates; (2) develop and field-test an emotional health brief assessment tool for children birth to 5 years old; (3) recommend to the service network methods of conducting comprehensive psychosocial assessments of children/families with emotional difficulties; (4) strengthen treatment services which facilitate attachment, interaction, mastery, and support within families; and (5) disseminate products and methods statewide and nationally.

TITLE: Promoting Success in Zero to Three Services

PRINCIPAL INVESTIGATOR: Carol Berman, M.A.
National Center for Clinical Infant Programs
2000 14th Street, North
Suite 380
Arlington, VA 22201

PHONE NUMBER: (703) 528–4300

PROJECT PERIOD: 07/01/89 – 06/30/94

SUMMARY:

The goal of this project is to improve systems of services for infants and toddlers with special health care needs and their families. The project will function as a national resource center on the needs of this special population. Over the 3-year funding period, the program will pursue two main objectives. The first is to identify and promote nationally examples of workable approaches to serving infants and toddlers with special health needs and their families. The second is to identify and promote community systems that use prevention approaches successfully so that they can be replicated nationwide.

TITLE: Statewide Linkage and Tracking Network of Early Identification and Early Intervention for 0–3 At-Risk and Disabled Infants

PRINCIPAL INVESTIGATOR: E. Elaine Vowels, Ph.D.
District of Columbia Commission of Public Health
1660 L Street, N.W.
Washington, DC 20036

PHONE NUMBER: (202) 727–3866

PROJECT PERIOD: 10/01/86 – 09/30/90

SUMMARY:

The goal of this project is to develop an information management system for early identification and intervention in order to improve the health outcome of infants and children birth to 3 years of age who have disabilities or are at risk for developing disabilities. Activities include establishing a centralized data bank and an integrated network service delivery system, as well as implementing a tracking system of the service delivery process.

Adolescents/Young Adults

TITLE: Adolescent ADM: Service Use and Risks of Co-Morbidity

PRINCIPAL INVESTIGATOR: Adrian Angold, M.B., M.R.C. Psych
Department of Psychiatry
Duke University Medical Center
Durham, NC 27710

PHONE NUMBER: (919) 687–4676

PROJECT PERIOD: 09/89 – 08/92

SUMMARY:

This research is concerned with response to treatment by substance abusing adolescents who have co-occurring psychiatric disorders as compared to adolescents with substance abuse only. Subjects are: (1) a consecutive sample of 150 adolescents aged 11–18 years referred to the substance abuse treatment program of a community child guidance clinic, (2) a consecutive sample of 100 adolescents aged 11–18 years referred to a day hospital substance abuse program, and (3) the parents of these adolescents. Data are also being collected from homeroom teachers. Each adolescent subject receives a full research diagnostic evaluation for substance abuse and psychiatric disorder at time of intake that includes detailed measures of psychosocial adjustment and service utilization during the preceding 4 months. Measures of drug use and psychiatric disturbance in the adolescents, service utilization by the adolescents, and teacher ratings are repeated for all adolescents at 4, 8, and 12 months after reception into treatment, with additional followup of the guidance clinic subjects at 18 and 24 months.

TITLE: A Social Cognition Program for Deaf Adolescents and Adults

PRINCIPAL INVESTIGATOR: Mimi Lou, Ph.D.
University of California—San Francisco
Center on Deafness
3333 California Street, Suite 10
San Francisco, CA 94143-1208

PHONE NUMBER: (415) 476–4980 (Voice)
(415) 476–7600 (TDD)

PROJECT PERIOD: 03/88 – 02/93

SUMMARY:

The purpose of this long-term project is to develop, implement, and evaluate a social-cognitive group program to raise the levels of social functioning of deaf adolescents and adults. The program aims to compensate for gaps and losses in the developmental social experience of those deaf individuals who are low-functioning by a group program which provides opportunities for mediated learning in the social domain. In other words, group activities are selected and/or developed which structure opportunities to think (understand and reason) about people, about relationships, and about social events and issues in a guided way. We hypothesize that if a program of mediated intervention can raise levels of social cognition (perspective taking, person conceptualization, communication, and social causal reasoning and problem-solving), then improved social and socio-emotional functioning will follow. The project design includes phases for development, piloting, refinement, and evaluation of the program with groups of deaf adolescents enrolled in high school and with groups of deaf adults not enrolled in any regular program. The evaluation phase includes, initially, development of a rating measure of social functioning for use by teachers and counselors, and finally, an experimental design comparing matched treatment and control groups for changes related to participation in the social-cognitive group program.

TITLE:	A Study of Successful Deaf High School Students
PRINCIPAL INVESTIGATOR:	Michael Strong, Ph.D. University of California—San Francisco Center on Deafness 3333 California Street, Suite 10 San Francisco, CA 94143-1208
PHONE NUMBER:	(415) 476–4980 (Voice); (415) 476–7600 (TDD)
PROJECT PERIOD:	11/89 – 02/93

SUMMARY:

This study is an investigation into social, linguistic, cognitive, and academic success among high school students with severe or profound hearing loss. The project is constructed as an in-depth investigation of a sample of 23 students, nominated by their teachers from schools in different parts of the country. Two teams of two researchers, one deaf and one hearing, visited each school site and interviewed the students and one or both parents of guardians separately, and videotaped the student and parent(s) conversing together. Parent interviews included the Vineland Scale of Social Adjustment, and questions about the family history especially as it related to the student. Interviews with the students included an examination of their levels of social cognition, and questions about their relationships, their schooling, their upbringing, why they thought they were successful, and their future plans. Nominating teachers also completed a questionnaire, students provided an on-the-spot writing sample, and information on standardized test scores and audiological and psychological examinations was obtained from school records. The results will be reported as a series of case studies, as well as a review of common themes. Separate sub-analyses will be conducted on the writing samples, the parent-student interactions, and the social cognition data.

TITLE: A Study of 18–22 Year Olds Who Are Completing Special Education Programs

PRINCIPAL INVESTIGATOR:
Karen Unger, Ed.D.
Center for Psychiatric Rehabilitation
Boston University
730 Commonwealth Avenue
Boston, MA 02215

PHONE NUMBER: (617) 353–3549

PROJECT PERIOD: 08/01/90 – 07/31/91

SUMMARY:

The purpose of this project is to study the experiences and problems confronting young adults, aged 18–22 years, who are completing their special education programs under P.L. 94–142. This project is being conducted in collaboration with the Florida Research and Training Center for Improved Services for Seriously Emotionally Disturbed Children (FRTC), Florida Mental Health Institute, University of South Florida, Tampa, Florida. As part of its overall program of research, FRTC has been conducting a longitudinal study entitled, "The National Adolescent and Child Treatment Survey (NACTS)." Utilizing existing data from that study, new instruments were jointly developed which were administered to a representative sample of 150 subjects who were 18 years of age or older, and their parents. The new instruments were focused on the transition process, particularly to work, school and independent living, from SED programs. Questions focused on services that were helpful and those that were not. The instruments were administered by FRTC staff who went into the field in June and July to conduct personal interviews with the young adults. Parent interviews were conducted by telephone during July and August. Year two of the project will include analysis and dissemination of the findings.

TITLE: Community Partners

PRINCIPAL INVESTIGATORS:

David Bateman, M.S.
Janet Williams, MSW
Beach Center on Families and Disability
3111 Haworth
The University of Kansas
Lawrence, KS 66045

PHONE NUMBER: (913) 864–7600

PROJECT PERIOD: 07/01/90 – 06/30/91

SUMMARY:

The community Partners Program is developing, implementing, evaluating, and disseminating social network strategies for promoting three goals for young adults with severe disabilities: 1) Self-determination, 2) Supported/competitive employment, and 3) Independent living. People served by the program are individuals who have exited from high school education within the past five years and have encountered significant barriers to achieving self-determination and their chosen vocational and independent living outcomes. The Partners approach builds on the "Circle of Friends" model in developing Partners groups to provide social support. Other strategies that are incorporated into the Partners model include: cooperative learning, peer counseling, peer tutoring, citizen advocacy, and self-advocacy.

Currently, seven individuals with severe disabilities and their families are receiving services and support. This project has:

- Completed a comprehensive review of literature on groups for promoting program goals;
- Developed and implemented a naturalistic inquiry investigation to document the process, procedures, and outcomes of the Community Partners program;
- Prepared three 1 1/2 hour teleworkshops to be disseminated to sites in approximately 25 states in the United States and Canada to describe the Community Partners model outline.

This project will:

- Develop, implement, and evaluate a training model to prepare community volunteers to serve as facilitators for new Partners groups;
- Serve an additional eight individuals with disabilities and their families with volunteer facilitators;
- Develop, implement, and evaluate a curriculum to increase the skills to individuals with severe disabilities in the area of self-determination;
- Prepare articles for peer-review journals and family newsletters and training manuals/video-tapes to disseminate results.

TITLE: Development and Evaluation of a Transitional Service Model for 18–22 Year Olds with Severe Emotional Disturbance

PRINCIPAL INVESTIGATOR: Karen Unger, Ed.D.

PHONE NUMBER: (617) 353–3549

PROJECT PERIOD: 08/01/90 – 07/31/91

SUMMARY:

This project, also conducted in collaboration with the Florida Research and Training Center for Seriously Emotionally Disturbed Children and Youth (FRTC), has been changed from developing and evaluating a model service program, to describing the current state-of-the-practice of transitional programs and conceptualizing a developmental model for 18–22 year olds. This change was made because of funding considerations. To meet the first objective, describing the current state-of-the-practice, criteria for inclusion as a "model transition program" was developed and a process for identifying those programs is being implemented. Program evaluation literature is being reviewed to help with the selection of model programs. To begin the process of conceptualizing a developmental model for 18–22 year olds, literature is being gathered and reviewed. Information from Project TE–1 will also be utilized to meet this objective. Additionally, experts in the developmental field are being identified and will be consulted.

TITLE: Development of a Prevocational Training Center

PRINCIPAL INVESTIGATOR:
Patience H. White, M.D.
Children's Hospital National Medical Center
111 Michigan Avenue, N.W.
Washington, DC 20010

PHONE NUMBER: (202) 745–3203

PROJECT PERIOD: 07/01/88 – 06/30/90

SUMMARY:

The goals of this project are to determine if early vocational guidance can improve vocational readiness in adolescents with rheumatic disease and to expand the project to encompass children with chronic illnesses. The program includes prevocational assessment and counseling; an employment resource guide; outreach to children, families, and employers in the region; and a computerized data base with prevocational data.

TITLE: Effectiveness of Case Management for Homeless Adolescents

PRINCIPAL INVESTIGATOR: Ana Marie Cauce, Ph.D.
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NI 25
University of Washington
Seattle, WA 98195

PHONE NUMBER: (206) 543-7438

PROJECT PERIOD: 10/90 – 09/93

SUMMARY:

Homeless adolescents are considered the most understudied of all homeless populations. In this project, investigators will develop, implement, and evaluate an intensive, adolescent-centered case management approach to treating homeless adolescents in Washington State. A comparison of the relative effectiveness of this program with current services within Seattle and minimal services in Everett will be made in the areas of residential stability, mental health, independent living skills, substance abuse, social functioning, education/employment history, quality of life, and consumer satisfaction. In addition, prevalence and distribution data with regard to mental illness among this cohort will be collected and a process evaluation will be conducted to determine which variables, including program implementation and adolescent characteristics, mediate client outcome.

TITLE: Evaluating the Characteristics and the Outcomes of Young Adults with Severe Psychiatric Disabilities

PRINCIPAL INVESTIGATOR:
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Center for Psychiatric Rehabilitation
Boston University
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Boston, MA 02215

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PROJECT PERIOD: 08/01/90 – 07/31/91

SUMMARY:

The purpose of this project is to describe the characteristics of, and the correlates and predictors of outcome among young adults with psychiatric disability. This study will address several important questions: who are young adults who experience severe psychiatric disabilities and how do they differ from other persons with psychiatric disabilities? How do outcomes differ between younger and older adults with psychiatric disabilities? What are the patterns of service use and outcomes over time for these persons? Why do some young adults with severe psychiatric disability drop out of psychosocial programs? What are their perceptions of their service needs and how those needs are, or are not being met in traditional programs? This project is being conducted in two phases: during the first phase of the project, a previous Center study will be continued. That study was a longitudinal investigation of subjects involved in psychosocial rehabilitation programs and collected data on demographic and clinical characteristics, vocational outcomes, psychiatric symptomatology, social supports, and so forth. Beginning in August, 1989, the longitudinal study was continued by continuing to study persons under the age of 35. The psychosocial programs participating in the study are: the Social Center for Psychiatric Rehabilitation in Fairfax, Virginia and Community Friendship in Atlanta, Georgia. The second phase of the study will be conducted by gathering new survey data from two groups of young adults: those who have dropped out of psychosocial programs and those who have remained in those programs. This data will allow us to understand and more effectively serve the population of young adults with psychiatric disability who are characterized as difficult to serve.

TITLE: Factors Related to Depression and Suicide Among Disadvantaged Adolescents

PRINCIPAL INVESTIGATORS: Drs. Roberta Clark, Eva Molnar, Sunita Saxena, Sylvia Walker and Charles Asbury
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Washington, DC 20001

PHONE NUMBER: (202) 806–8727

PROJECT PERIOD: 07/01/88 – 06/30/90

SUMMARY:

Purpose/Objective: This project will assess the prevalence of depression and/or suicidal ideation in economically disadvantaged male and female adolescents. Various factors such as demographic characteristics, health support systems, interpersonal relationships, sexual activity and life stresses will be studied in terms of the extent to which they relate to depression *and* suicide.

Methodology: Forty-five subjects were recruited from among over 500 youth participating in the DC Job Corps. Their ages ranged from 13 to 18 years and both males and females were included in the sample.

Subjects were administered the Reynold's Adolescent Depression Scale, the Reynold's Suicidal Ideation Questionnaire and an author constructed confidential information questionnaire.

Current Status: All instruments have been administered to the sample of subjects. These instruments have yet to be scored and the resulting data processed and prepared for analysis. At present all activity on the project is limited for further explorations of the literature.

The next phase will involve an analysis of the data to test hypotheses raised in connection with various aspects of the relationship of suicide and depression to such factors as demographic characteristics, support systems and life stresses. Upon completion of these analyses, the results will be summarized and discussed in a report and prepared for publication and dissemination.

TITLE: Family Autonomy Project

PRINCIPAL INVESTIGATOR: Sharon L. Hostler, M.D.
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Kluge Children's Rehabilitation Center
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Charlottesville, VA 22901

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PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

The goal of this project is to ensure the successful transition to adulthood of adolescents with physical disabilities or chronic illnesses by means of interventions with families, the health care team, and the adolescents themselves. The project seeks to encourage the involvement of families in planning for the health care of their children, to modify staff behaviors and institutional practices to promote family autonomy, and to broaden treatment goals so that they include health maintenance and future planning for adolescents with special needs.

TITLE: Family Coping Strategies and Their
Relation to Rehabilitation Outcomes Among
Young Adults With Mental Illness

PRINCIPAL INVESTIGATOR: Mardi Solomon, Ph.D.
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PROJECT PERIOD: 09/30/90 – 09/29/95

SUMMARY:

The purpose of the proposed research project is to compare the degree of burden experienced by parents of severely mentally ill offspring with the degree of burden reported by a group of parents of same-aged offspring who are not mentally ill and who reside in the same geographic and socio-economic neighborhoods of Chicago, Illinois. This will be done to address several questions regarding both objective aspects of familial burden such as strain on family finances and deterioration of social support networks, and subjective aspects of burden such as feelings of depression and anxiety, as well as their relation to ill offsprings' rehabilitation outcomes. First, affected parents' self-esteem, coping mastery and morale will be compared to levels found among parents of "normal" offspring. Second, the attitudes of affected parents toward the mental health professions will be compared with those of the non-affected group of parents. Third, affected parents' experiences with a series of problems identified in the literature on parental burden among family caretakers will be compared to many parents of "normal" children. Fourth, the levels of physical and emotional symptomatology experienced by affected parents will be compared with levels reported by parents of non-disabled offspring. Finally, parents' degree of burden will be correlated with their offsprings' eventual rehabilitation outcomes in the residential, vocational, and recidivism areas. At present, data addressing these questions from 222 parents of mentally ill offspring entering a psychiatric rehabilitation program have been collected, coded, and entered in the computer. The task at hand at present, then, is to collect the same information from a group of parents of adult offspring who are not afflicted with psychiatric disability. A community college on the North side of Chicago has agreed to allow its Alumni Association to supply names and addresses of target age parents as well as an endorsement of the project and its aims. Alumni parents will then complete the study instruments and return them by mail. This will allow matching parents of similar age offspring, from similar areas of Chicago, and at similar educational levels.

TITLE: HMO and Psychiatric Child Assessments: A Follow-up Study

PRINCIPAL INVESTIGATOR: Elizabeth Costello, Ph.D.
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Durham, NC 27710

PHONE NUMBER: (919) 684–3932

PROJECT PERIOD: 09/89 – 08/92

SUMMARY:

The aim of this study is to examine the mental health and level of functioning at home, at school, and with peers of 434 adolescents who were at first studied five years ago, using similar measures. One group (N = 300) was recruited from the pediatric clinics of a Health Maintenance Organization (HMO); many had mental health problems that were not recognized or treated. The other group (N = 134) received treatment at a child psychiatric clinic in the same community. The study will examine: (1) continuity and change in mental health problems, (2) childhood predictors of mental health and social functioning in adolescence, and (3) the effect of using mental health services on the outcomes of childhood psychopathology.

TITLE: Implementation and Evaluation of Psychosocial Services for Adolescents with Genetic Diseases

PRINCIPAL INVESTIGATOR: Barry R. Sherman, Ph.D.
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Bureau of Child and Adolescent Health
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Albany, NY 12237-0618

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PROJECT PERIOD: 10/01/84 – 09/30/90

SUMMARY:

This project aims to develop a model support program for the coordination and integration of psychosocial support services in order to meet the special needs of genetically affected adolescents and their families. An interdisciplinary team approach to care coordination and management will be used, emphasizing individual, family, and community resources for a more comprehensive and holistic response to the needs of these adolescents and their families.

TITLE: National Center for Youth with Disabilities

PRINCIPAL INVESTIGATOR: Robert Wm. Blum, M.D., M.P.H., Ph.D.
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Adolescent Health Program
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Harvard Street at East River Road
Minneapolis, MN 55455

PHONE NUMBER: (612) 626–2825

PROJECT PERIOD: 10/01/89 – 06/30/94

SUMMARY:

The National Center for Youth with Disabilities (NCYD) is a technical assistance and resource center whose goal is to improve the health and social functioning of youth with disabilities by providing consultation and disseminating information to those who plan and deliver services and by increasing coordination between the health care system and other service providers. In order to meet its goal, NCYD will maintain the National Resource Library, provide assistance directly or through the Technical Assistance Network, distribute a quarterly newsletter, and conduct national and regional meetings for parents and professionals.

TITLE: National Study of Transition from School to Work for Deaf Youth

PRINCIPAL INVESTIGATOR: Afaf El-Khiami, Ph.D.
University of Arkansas, Rehabilitation
Research and Training Center on
Deafness and Hearing Impairment
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Little Rock, AR 72205

PHONE NUMBER: (501) 371–1654 (V/TDD)

PROJECT PERIOD: 1986 – 1991

SUMMARY:

This research project was designed to conduct a national study to examine the variations that exist in cooperative transitional programs involving state vocational rehabilitation agencies and special education programs serving deaf and hard of hearing students. A particular focus on this project is to determine how educational and rehabilitation collaboration are structured and implemented and to assess the extent to which deaf students and their families are full participants in the transition process. The field presently lacks an organized body of knowledge from which to generate adequate answers and strategies. In designing this application, we targeted the three central players in the transition process: (1) the school, 2) the student/parents, and 3) the state vocational rehabilitation agency in the various states.

TITLE: Networking Services for Adolescents with Sickle Cell Disease: An Interdisciplinary Demonstration Project

PRINCIPAL INVESTIGATOR: Pearlie Fennell, Ph.D.
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Houston, TX 77054

PHONE NUMBER: (713) 666–0300

PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

This project will develop a network of coordinated psychosocial community services designed to address the unmet psychosocial needs of adolescents with sickle cell disease and to assist these individuals in preparation for a productive adulthood. The program will focus on enhancing the self-concept and self-esteem of the adolescents enrolled in the program.

TITLE: Physical Functioning and Motor Outcomes of Injured Children and Adolescents

PRINCIPAL INVESTIGATOR:
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New England Medical Center
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Boston, MA 02111

PHONE NUMBER: (617) 956–5031

PROJECT PERIOD: 01/01/88 – 12/31/92

SUMMARY:

Children with traumatic injuries frequently exhibit residual physical and functional motor deficits. The major goal of this project is to examine the physical functioning and motor recovery of children and adolescents after a traumatic injury. Contributing clinical sites are the Kiwanis Pediatric Trauma Institute at Floating Hospital for Infants and Children, Boston, MA and Baystate Medical Center, Springfield, MA. Physical and functional motor outcomes are being examined at hospital discharge, one month, three months, and six months after hospital discharge. Pre-injury data (retrospective from parents) includes the social competence and activity scale of the Child Behavior Checklists and the physical health section of the Rand Child Health Scale. Measurements taken at hospital discharge are the short form of the Scales of Independent Behavior and the Fine Motor Section of the Bruininks-Oseretsky Test of Motor Proficiency. General measures of physical function and activity taken at one, three, and six months are the physical scales of the Child Health Scale. More specific and detailed measures taken at one and six months post-discharge on those children who are able to return for a follow-up visit are the Scales of Independent Behavior, the gross and fine motor sections of the Bruininks-Oseretsky Test of Motor Proficiency, and the social competence and activity scales of the Child Behavior Checklist. Outcomes will include: 1) the description and frequency of motor and functional outcomes after injury, and 2) the differential pattern of injury related problems across severity levels of trauma.

TITLE:	Psychosocial and Family Outcomes of Injured Children and Adolescents
PRINCIPAL INVESTIGATOR:	Donald Wertlieb, Ph.D. Department of Rehabilitation Medicine Tufts University School of Medicine New England Medical Center 750 Washington St #75K–R Boston, MA 02111
PHONE NUMBER:	(617) 956–5031
PROJECT PERIOD:	01/01/88 – 12/31/92

SUMMARY:

Rehabilitation services for childhood trauma include a broad array of child and family interventions to enhance the recovery process. Rehabilitation programs are not complete, nor are they likely to be effective if the negative psychosocial impact of injury on children and families is not adequately addressed. The major goal of this project is to understand the nature and extent of child and family psychosocial problems after traumatic injury. Contributing clinical sites are the Kiwanis Pediatric Trauma Institute at Floating Hospital for Infants and Children, Boston, MA. A battery of measures assess child and family psychosocial status as well as school reintegration status at one month and again at six month post discharge. The measures include the Child Behavior Checklist, the Impact of Family Scale and School Reintegration Checklist. At the six-month follow-up, an additional measure is introduced with a Teacher Questionnaire to assess school behavior and academic performance. Outcomes of this project will include: 1) the description and frequency of child behavior problems, family disruption and stress, and school reintegration problems after injury, 2) the differential pattern of injury related psychosocial and school problems across varying trauma severity levels, and 3) the extent of recovery of behavior, psychosocial and school problems for injured children over a six-month periods, and how psychosocial factors relate to injury recovery.

TITLE: RTC in Rehabilitation and Childhood Trauma Project: National Pediatric Trauma Registry

PRINCIPAL INVESTIGATOR:

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PHONE NUMBER: (617) 956–5031

PROJECT PERIOD: 01/01/88 – 12/31/92

SUMMARY:

The National Pediatric Trauma Registry (NPTR) is a collection of information about unintentional injuries occurring in children and young adults admitted to trauma centers for treatment. Started in April 1985, it currently includes about 22,000 cases of injuries and is increasing at a rate of approximately 6,000 cases a year.

The Registry is supported by the American Pediatric Surgical Association (APSAP) and data to the Registry are contributed by 50 trauma centers of children's hospitals on a voluntary basis.

The data collected in the Registry includes demographics, detailed description of the injury event, management of the victim at the scene, severity at the time of admission to the trauma center, management at the trauma center, discharge status, functional assessment at discharge, diagnoses and procedures performed.

Measures of severity include Abbreviated Injury Scale (AIS), Injury Severity Score (ISS), Glasgow Coma Scale (GCS), and Pediatric Trauma Score (PTS). Functions at discharge are assessed by a checklist of daily activities as well as by the Functional Independence Measure (FIM), where applicable. Diagnosis and procedure are recorded using the ICD-9 CM codes. The external causes of injury and accident scene are recorded using E-codes.

The Registry encompasses many aspects of pediatric trauma. It has been used to document pediatric injury outcome and to assess acute and rehabilitative treatment efficacy. Work is currently in progress to quantify morbidity resulting from injuries and to identify predictions of long-term outcomes.

TITLE:	Service and Mental Health Needs of Adopted Adolescents
PRINCIPAL INVESTIGATOR:	Peter L. Benson, Ph.D. Search Institute 122 West Franklin Avenue, Suite 525 Minneapolis, MN 55404
PHONE NUMBER:	(612) 870–9511
PROJECT PERIOD:	09/89 – 08/93

SUMMARY:

Records of mental health clinics show that adopted children are referred to mental health professionals at a rate far exceeding their representation in the general population. The goal of Dr. Benson's research is to develop improved information on emotional and behavioral problems in adopted adolescents that can help to guide and enhance delivery of services to adopted adolescents and their families. Surveys will be administered to approximately 1,680 adoptive parents, 1,260 adopted adolescents (ages 12–18), and 420 non-adopted adolescents (ages 12–18) randomly selected from the placement records of 40 private and 30 public located in Illinois, Minnesota, Wisconsin and Colorado.

TITLE: Social Transition of Deaf Seniors

PRINCIPAL INVESTIGATOR: Randolph Mowry, Ph.D.
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Research and Training Center on
Deafness and Hearing Impairment
4601 West Markham Street
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PHONE NUMBER: (501) 371–1654 (V/TDD)

PROJECT PERIOD: 09/86 – 09/91

SUMMARY:

This study investigates the "social transition" of deaf high school students from high school to postsecondary or community settings. Social transition refers to the changes that occur in the social relationships of deaf students related to graduation, and how these social changes influence the student's psychological adjustment. Graduation involves significant changes in the graduate's roles, and responsibilities can be stressful. This stress occurs when the graduate's social networks are changing, reducing the resources of information and support for successful coping and possibly causing problems in adjustment.

This study documents the changes in the student's networks and social support, the degree of stress experienced, and adjustment. The results will be used to develop an intervention to help students recognize the upcoming changes, and provide them with techniques to manage the changes.

Two hundred deaf students in the mid- and south-west from residential and public school programs completed a questionnaire prior to graduation from high school that measured adjustment, social networks and support, and stress; 93 graduates completed the postgraduation questionnaire measuring the same variables. The two assessments permit documentation of changes the students have experienced.

TITLE: Specialized Family ER Program with Suicide Attempters

PRINCIPAL INVESTIGATOR:
Mary J. Rotheram-Borus, Ph.D.
Research Foundation for Mental Hygiene
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PHONE NUMBER: (212) 740–7323

PROJECT PERIOD: 09/90 – 08/95

SUMMARY:

Since family factors are of critical importance in understanding adolescent suicide attempts and are also important determinants of compliance with recommended treatment, Dr. Borus will be evaluating the effectiveness of a specialized emergency room (ER) family intervention for a consecutive series of 200 female suicide attempters aged 12–18 who are predominantly Black and Hispanic. Female suicide attempters will receive either standard ER care plus brief family therapy or a specialized ER program and brief family therapy. The specialized program will include: 90 minute crisis family intervention; a brief videotape about what families can expect therapy in therapy; training for staff in the ER, child psychiatry, and adult psychiatry on adolescent suicidality. Number of suicide reattempts and suicide-related risk factors will be assessed at 3, 6, 12, and 18 months.

TITLE: The Career Development Experiences and Career Decisions of Deaf High School Seniors

PRINCIPAL INVESTIGATOR: John Schroedel, Ph.D.
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PHONE NUMBER: (501) 371–1654 (V/TDD)

PROJECT PERIOD: 09/86 – 03/90

SUMMARY:

Methods: Interviews with 189 deaf seniors graduating from 16 residential and day high schools revealed each senior's career decision, experiences with career development activities in and out of school, and plans after graduation. School staff evaluated the career decision, career decision-making skills, and probable post-high school placement for each senior.

Results: Comparisons between the seniors from the two sets of high schools yielded some significant differences. In contrast to their peers in the day high schools, residential seniors received more vocational interest testing and vocational training. Larger proportions of day school seniors, however, experienced work-study assignments and career counseling. Residential seniors more so than their counterparts in the day high schools were rated to be more knowledgeable about their vocational aptitudes and were more likely to consider other occupations before making their career decisions.

Exposure to certain career learning activities was found to be related to specific career decision-making skills and amount of interest in one's career choice. This latter factor, in turn, was associated with more motivation about postsecondary training. Analyses determined that seniors who had experienced vocational training were rated as more knowledgeable about their vocational skills and were more likely to consider other careers prior to making their career decisions than were seniors who had not experienced vocational training. In addition, seniors who had received career counseling compared to those who had not were rated as being more knowledgeable about the skills needed to enter their chosen careers as well as being more interested in their career choices. Amount of interest in one's career choice was related to amount of motivation towards the postsecondary placement, rated readiness for that placement, and rated prospects for completing training at that placement.

TITLE: The National Adolescent and Child Treatment Study (NACTS)

PRINCIPAL INVESTIGATORS:
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Starr Silver, Ph.D.
Research and Training Center for
Children's Mental Health
University of South Florida
Florida Mental Health Institute
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PROJECT PERIOD: 09/28/89 – 09/27/94

SUMMARY:

The purpose of this observational study is to describe the characteristics, functional levels, receipt of services, and outcomes among a large (N = 812) sample of children and adolescents with serious emotional problems. This project is a seven-year longitudinal study that was initiated by the Center in 1984. The sample is comprised of children who, at the time of initial data collection, resided in six states. Within each state, approximately half of the sample was obtained from children served in special education programs, and half from residential mental health facilities. Three age cohorts are being studied: pre-adolescents (ages 8 to 11), adolescents (ages 12 to 14), and older adolescents (ages 15 to 18). The National Adolescent and Child Treatment Study (NACTS) is collecting data from the youngsters and their parents and is providing important epidemiological and systems knowledge on such issues as the duration of childhood psychopathology, the services received by this sample (including those received as children progress to early adulthood), the long-term outcomes among the youngsters, and key predictors of these outcomes.

TITLE: Transition from School to Work

PRINCIPAL INVESTIGATOR:
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Research and Training Center in
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PHONE NUMBER: (501) 575–3656 (Voice or TDD)

PROJECT PERIOD: 03/01/88 – 02/28/93

SUMMARY:

This project seeks to develop strategies and techniques that will enable special and vocational education and vocational rehabilitation agencies to work together to assist both employers and disabled youth in the transition from school to work. Research is being conducted on a statewide interagency collaboration process leading to the development and testing of models demonstrated in selected schools.

TITLE: Transition from School to Work: Assessing Employment-Related Needs of Disabled Youth Exiting Public Schools and the Role of Facilities in Meeting Those Needs

PRINCIPAL INVESTIGATOR:
Rehabilitation Research and Training Center
Education and Human Services Building
University of Wisconsin–Stout
Menomonie, WI 54751

PHONE NUMBER:
(715) 232–1389
(715) 232–2251 (FAX)

PROJECT PERIOD: 03/88 – 02/91

SUMMARY:

The purposes of this project are to further refine the assessment of employment-related needs of youth with disabilities exiting public schools by combining, synthesizing, and prioritizing current knowledge regarding the transitional needs of school-exiting youth and to identify the role of community-based facilities in helping to meet these transitional needs. A thorough review of the existing literature in the area of transition from school to work was conducted and an initial compendium of transition needs was developed. These findings are being evaluated, integrated, and classified (e.g., in relation to the student, community, school) in terms of their potential importance and relevance to the transition process.

A nominal group approach is being used to arrive at consensus regarding the role of facilities as a resource in meeting these needs. The sample is stratified to include consumers, advocates, rehabilitation and education practitioners, university educators, and policy makers. The results of these consensus building activities will provide recommendations which community-based facilities may use to identify and prioritize transitional needs of school-exiting youth in their communities and identify the resources and services which they could provide to assist in meeting those needs.

TITLE: University of Washington Adolescent/Young Adult Transition Program

PRINCIPAL INVESTIGATOR: James A. Farrow, M.D.
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Division of Adolescent Medicine
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PHONE NUMBER: (206) 545–1273

PROJECT PERIOD: 10/01/88 – 09/30/91

SUMMARY:

The Adolescent Transition Program addresses the needs of older adolescents with special health care needs who wish to make the transition from pediatric to adult health care. An interdisciplinary team assesses patients for transition readiness and provides patient teaching as well as the identification of appropriate providers in the adult care section. Other objectives include a comparison of costs of health care in the pediatric and adult sectors, inservice training on the needs of this population, and community dissemination of a transition model.

TITLE: Young Adults in State Health Care Programs

PRINCIPAL INVESTIGATOR: Henry T. Ireys, Ph.D.
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1300 Morris Park Avenue
Bronx, NY 10461

PHONE NUMBER:

PROJECT PERIOD: 10/01/89 – 09/30/91

SUMMARY:

State Programs for Children with Special Health Care Needs have begun to recognize and address the pervasive difficulties that face chronically ill and handicapped older adolescents and young adults as they are discharged from these programs. Difficulties include problems in finding medical and related services responsive to their needs, inadequate financial coverage of needed services, psychological distress, and disincentives for vocational training or employment. At the present time, State programs lack the information needed for planning or developing services that would assist their population in their transition to adulthood. The general goal of this study is to help repair this deficit of knowledge through a survey of 1,000 adolescents and young adults who use these programs.

Transition and Independence Focus

TITLE: A Study of Youth in Transition

PRINCIPAL INVESTIGATORS:
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Research and Training Center for
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Florida Mental Health Institute
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PHONE NUMBER: (813) 974–4500

PROJECT PERIOD: 09/27/89 – 09/28/94

SUMMARY:

The purpose of this project is to specifically determine the factors associated with a successful transition from school to work, and from family or institutional living to independent living for a subsample of young adults participating in the National Adolescent and Child Treatment Study (NACTS). The study is being conducted in collaboration with the Center for Psychiatric Rehabilitation at Boston University. The study queries both the young adults and their parents about factors that have facilitated or blocked the attainment of key outcomes such as educational attainment, living in the community, being employed, and being involved in a social network.

TITLE: An Evaluation of Family and LEA Decisions Regarding the Appropriate Placement of Children with Technology Support

PRINCIPAL INVESTIGATOR: Pat Barber, Ph.D.
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The University of Kansas
Lawrence, KS 66045

PHONE NUMBER: (913) 864–7600

PROJECT PERIOD: 07/01/90 – 06/30/91

SUMMARY:

As an increasing number of children supported by medical technology move from the confines of health care institutions to home and community settings, school systems and families are beginning to face the challenge of providing appropriate educational services to meet the unique needs of these students. Service provision as well as the appropriate integration of many of these children into educational settings will depend on the resolution of such issues as health care costs, liability, personnel training, assessment, and the coordination of health, education, family, and related service systems. Current educational and health policies provide minimal guidance in addressing these and other factors affecting placement and the provision of services. To date, there is limited information on how service and placement decisions are made for these students. This project has:

- Completed and disseminated an Annotated Bibliography and completed and disseminated a literature review on educational services to children who are chronically ill and technology-supported;
- Contacted or interviewed by telephone over 60 parents and professionals across the country who have experience working with children who are ventilator-assisted in order to gather information about the characteristics and service needs of these children and the educational services issues related to this population;
- Conducted pilot interviews with parents of children who are ventilator-assisted, physicians, and educators as a means of confirming and supplementing information on educational service issues reported in the literature and through telephone contacts.

This project will:

- Conduct research on the factors affecting educational placement and service decisions through surveys and interviews with families of children who are ventilator-assisted and LEAs serving these children in at least six states;
- Disseminate research results through the development of a research monograph, journal articles aimed at special educators, school administrators, and school health personnel, and a handbook of "how-to" articles on practical information for families who participate in educational decisions.

TITLE: Community Transition Center

PRINCIPAL INVESTIGATOR:

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Education and Human Services Building
University of Wisconsin–Stout
Menomonie, WI 54751

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(715) 232–2251 (FAX)

PROJECT PERIOD: 12/87 – 02/91

SUMMARY:

The Community Transition Center (CTC) is a way of conceptualizing and organizing the employment related needs of youth with mild handicaps exiting the secondary public schools. The Model was based on a number of successful principles in the other projects (D'Alonzo & Owen, 1985) and on those identified in Project ADAPT (Thomas, Coker & McCray, 1988) which increased the ability of secondary schools to provide transition programs for their mildly handicapped youth. The model emphasizes the lead role of the secondary school system in initiating transition programming, the need for the school to establish work experience programs, and the establishment of an active network between the secondary school and post-secondary settings to assist students in their transition from school to the community. This program was targeted toward rural secondary-aged learning disabled and other mildly handicapped students who have been totally or partially mainstreamed into general education classes.

The CTC Model was tested in six different school districts in West Central Wisconsin. The project had four main objectives in facilitating transition programming in this region: (a) Increase the capacity of secondary schools to provide employment preparation skills to their handicapped youth; (b) increase the ability of post-secondary settings to educate or employ these youth, (c) provide direct services to these youth to assist in the transition process, and (d) develop training conferences, curriculum materials, and disseminate findings.

TITLE: Development and Evaluation of a Transitional Service Model for 18–22 Year Olds with Severe Emotional Disturbance

PRINCIPAL INVESTIGATOR: Karen Unger, Ed.D.

PHONE NUMBER: (617) 353-3549

PROJECT PERIOD: 08/01/90 – 07/31/91

SUMMARY:

This project, also conducted in collaboration with the Florida Research and Training Center for Seriously Emotionally Disturbed Children and Youth (FRTC), has been changed from developing and evaluating a model service program, to describing the current state-of-the-practice of transitional programs and conceptualizing a developmental model for 18–22 year olds. This change was made because of funding considerations. To meet the first objective, describing the current state-of-the-practice, criteria for inclusion as a "model transition program" was developed and a process for identifying those programs is being implemented. Program evaluation literature is being reviewed to help with the selection of model programs. To begin the process of conceptualizing a developmental model for 18–22 year olds, literature is being gathered and reviewed. Information from Project TE–1 will also be utilized to meet this objective. Additionally, experts in the developmental field are being identified and will be consulted.

TITLE: Development of a Prevocational Training Center

PRINCIPAL INVESTIGATOR: Patience H. White, M.D.
Children's Hospital National Medical Center
111 Michigan Avenue, N.W.
Washington, DC 20010

PHONE NUMBER: (202) 745-3203

PROJECT PERIOD: 07/01/88 – 06/30/90

SUMMARY:

The goals of this project are to determine if early vocational guidance can improve vocational readiness in adolescents with rheumatic disease and to expand the project to encompass children with chronic illnesses. The program includes prevocational assessment and counseling; an employment resource guide; outreach to children, families, and employers in the region; and a computerized data base with prevocational data.

TITLE:	Families and Communities in Transition
PRINCIPAL INVESTIGATOR:	Kathy Schwaninger SKIP of New York, Inc. 500 East 83rd Street, Suite 1B New York, NY 10028
PHONE NUMBER:	(212) 734–0728
PROJECT PERIOD:	07/01/87 – 06/30/90

SUMMARY:

The purpose of this project is to encourage and expand home care as an option for families of children with special health needs. Objectives include empowering families who choose home care with the necessary skills and knowledge to become their own effective case managers; creating a collaborative system between parents and professionals in planning and caring for children; and improving and expanding both current home health and other community service provisions for children and their families.

TITLE:	Family Autonomy Project
PRINCIPAL INVESTIGATOR:	Sharon L. Hostler, M.D. University of Virginia Kluge Children's Rehabilitation Center 2270 Ivy Road Charlottesville, VA 22901
PHONE NUMBER:	(804) 924–2345
PROJECT PERIOD:	10/01/87 – 09/30/90

SUMMARY:

The goal of this project is to ensure the successful transition to adulthood of adolescents with physical disabilities or chronic illnesses by means of interventions with families, the health care team, and the adolescents themselves. The project seeks to encourage the involvement of families in planning for the health care of their children, to modify staff behaviors and institutional practices to promote family autonomy, and to broaden treatment goals so that they include health maintenance and future planning for adolescents with special needs.

TITLE: Identification of Model Programs to Assist Transition from School to Work and Independent Living

PRINCIPAL INVESTIGATORS:
Hewitt Clark, Ph.D.
Karen Unger, M.S.W., Ed.D.
University of South Florida
Florida Mental Health Institute
13301 Bruce B. Downs Boulevard
Tampa, FL 33612

PHONE NUMBER: (813) 974–4500

PROJECT PERIOD: 09/27/89 – 09/28/94

SUMMARY:

The purpose of this research project is the identification of model programs which assist youth and young adults with severe emotional disturbances in transitioning from school to work and independent living. In collaboration with the Center for Psychiatric Rehabilitation at Boston University, the Florida Center has formulated program criteria which are being used to select programs which will be visited for greater in-depth study. This project should yield information regarding exemplary practices which help these youths during this transition period. The selected programs will be studied in 1990 and early 1991 and the results published in 1992.

TITLE: National Center for Youth with Disabilities

PRINCIPAL INVESTIGATOR:
Robert Wm. Blum, M.D., M.P.H., Ph.D.
University of Minnesota
Adolescent Health Program
Box 721 UMHC
Harvard Street at East River Road
Minneapolis, MN 55455

PHONE NUMBER: (612) 626–2825

PROJECT PERIOD: 10/01/89 – 06/30/94

SUMMARY:

The National Center for Youth with Disabilities (NCYD) is a technical assistance and resource center whose goal is to improve the health and social functioning of youth with disabilities by providing consultation and disseminating information to those who plan and deliver services and by increasing coordination between the health care system and other service providers. In order to meet its goal, NCYD will maintain the National Resource Library, provide assistance directly or through the Technical Assistance Network, distribute a quarterly newsletter, and conduct national and regional meetings for parents and professionals.

TITLE: National Study of Transition from School to Work for Deaf Youth

PRINCIPAL INVESTIGATOR: Afaf El-Khiami, Ph.D.
University of Arkansas, Rehabilitation Research and Training Center on Deafness and Hearing Impairment
4601 West Markham Street
Little Rock, AR 72205

PHONE NUMBER: (501) 371–1654 (V/TDD)

PROJECT PERIOD: 1986 – 1991

SUMMARY:

This research project was designed to conduct a national study to examine the variations that exist in cooperative transitional programs involving state vocational rehabilitation agencies and special education programs serving deaf and hard of hearing students. A particular focus on this project is to determine how educational and rehabilitation collaboration are structured and implemented and to assess the extent to which deaf students and their families are full participants in the transition process. The field presently lacks an organized body of knowledge from which to generate adequate answers and strategies. In designing this application, we targeted the three central players in the transition process: (1) the school, 2) the student/ parents, and 3) the state vocational rehabilitation agency in the various states.

TITLE: Operational Definition of Independence

PRINCIPAL INVESTIGATOR: Marcus Fuhrer, Ph.D.
Research and Training Center—Independent Living
3400 Bissonnett – Suite 101
Houston, TX 77005

PHONE NUMBER: (713) 666–6244

PROJECT PERIOD:

SUMMARY:

This project is designed to develop an operational definition of independence that incorporates three dimensions of the term: perceptions of control over one's life, psychological factors, and behavioral or functional characteristics. The objective is to develop an assessment instrument to quantify an individual's independence in each of the above domains.

TITLE: Reasonable Efforts in Permancy Planning

PRINCIPAL INVESTIGATOR: Christopher Petr, Ph.D.
Beach Center on Families and Disability
3111 Haworth
The University of Kansas
Lawrence, KS 66045

PHONE NUMBER: (913) 864–7600

PROJECT PERIOD: 07/01/90 – 06/30/91

SUMMARY:

Children with disabilities often seem to be high risks for out-of-home placement. This project will develop a state-of-the-art definition of "reasonable efforts" to maintain children with emotional disorders (ED), developmental disabilities (DD), and technology support (TS) in permanent placements in the least restrictive environment. The overall research question is: What state policies, programs, supports, and values regarding "reasonable efforts" are the most conducive to maintaining those children with emotional disorders, developmental disabilities, and technology support in the least restrictive, most home-like environments?

To answer this question, we will investigate two aspects of this issue during the first two years of the project. The first involves a policy analysis of one exemplary state's current "reasonable efforts." The second centers on understanding the stresses faced by families and the match between their needs and the same state's "reasonable efforts."

This project has:

- Begun data collection and analysis.

This project will:

- Complete data collection and analysis;
- Initiate educational and other change efforts to achieve implementation of the state-of-the-art definition of "reasonable efforts" in one or two targeted states;
- Work with family organizations, service providers, and policy makers;
- Submit the policy analysis for publication in a peer-reviewed journal;
- Prepare a manual on change efforts for family organizations;
- Present the content of the manual at annual meetings of family and provider organizations.

TITLE: Social Transition of Deaf Seniors

PRINCIPAL INVESTIGATOR: Randolph Mowry, Ph.D.
University of Arkansas, Rehabilitation Research and Training Center on Deafness and Hearing Impairment
4601 West Markham Street
Little Rock, AR 72205

PHONE NUMBER: (501) 371-1654 (V/TDD)

PROJECT PERIOD: 09/86 – 09/91

SUMMARY:

This study investigates the "social transition" of deaf high school students from high school to postsecondary or community settings. Social transition refers to the changes that occur in the social relationships of deaf students related to graduation, and how these social changes influence the student's psychological adjustment. Graduation involves significant changes in the graduate's roles, and responsibilities can be stressful. This stress occurs when the graduate's social networks are changing, reducing the resources of information and support for successful coping and possibly causing problems in adjustment.

This study documents the changes in the student's networks and social support, the degree of stress experienced, and adjustment. The results will be used to develop an intervention to help students recognize the upcoming changes, and provide them with techniques to manage the changes.

Two hundred deaf students in the mid- and south-west from residential and public school programs completed a questionnaire prior to graduation from high school that measured adjustment, social networks and support, and stress; 93 graduates completed the postgraduation questionnaire measuring the same variables. The two assessments permit documentation of changes the students have experienced.

TITLE: Transition from School to Work

PRINCIPAL INVESTIGATOR: Reed Greenwood, Ed.D.
University of Arkansas—Arkansas
Research and Training Center in
Vocational Rehabilitation
346 North West Avenue
Fayetteville, AK 72701

PHONE NUMBER: (501) 575–3656 (Voice or TDD)

PROJECT PERIOD: 03/01/88 – 02/28/93

SUMMARY:

This project seeks to develop strategies and techniques that will enable special and vocational education and vocational rehabilitation agencies to work together to assist both employers and disabled youth in the transition from school to work. Research is being conducted on a statewide interagency collaboration process leading to the development and testing of models demonstrated in selected schools.

TITLE: Transition from School to Work: Assessing Employment-Related Needs of Disabled Youth Exiting Public Schools and the Role of Facilities in Meeting Those Needs

PRINCIPAL INVESTIGATOR:
Rehabilitation Research and Training Center
Education and Human Services Building
University of Wisconsin–Stout
Menomonie, WI 54751

PHONE NUMBER:
(715) 232–1389
(715) 232–2251 (FAX)

PROJECT PERIOD: 03/88 – 02/91

SUMMARY:

The purposes of this project are to further refine the assessment of employment-related needs of youth with disabilities exiting public schools by combining, synthesizing, and prioritizing current knowledge regarding the transitional needs of school-exiting youth and to identify the role of community-based facilities in helping to meet these transitional needs. A thorough review of the existing literature in the area of transition from school to work was conducted and an initial compendium of transition needs was developed. These findings are being evaluated, integrated, and classified (e.g., in relation to the student, community, school) in terms of their potential importance and relevance to the transition process.

A nominal group approach is being used to arrive at consensus regarding the role of facilities as a resource in meeting these needs. The sample is stratified to include consumers, advocates, rehabilitation and education practitioners, university educators, and policy makers. The results of these consensus building activities will provide recommendations which community-based facilities may use to identify and prioritize transitional needs of school-exiting youth in their communities and identify the resources and services which they could provide to assist in meeting those needs.

TITLE: University of Washington Adolescent/
Young Adult Transition Program

PRINCIPAL INVESTIGATOR: James A. Farrow, M.D.
University of Washington
Division of Adolescent Medicine
CDMRC, WJ-10
Seattle, WA 98195

PHONE NUMBER: (206) 545–1273

PROJECT PERIOD: 10/01/88 – 09/30/91

SUMMARY:

The Adolescent Transition Program addresses the needs of older adolescents with special health care needs who wish to make the transition from pediatric to adult health care. An interdisciplinary team assesses patients for transition readiness and provides patient teaching as well as the identification of appropriate providers in the adult care section. Other objectives include a comparison of costs of health care in the pediatric and adult sectors, inservice training on the needs of this population, and community dissemination of a transition model.

TITLE: A Social Cognition Program for Deaf Adolescents and Adults

PRINCIPAL INVESTIGATOR: Mimi Lou, Ph.D.
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Center on Deafness
3333 California Street, Suite 10
San Francisco, CA 94143-1208

PHONE NUMBER: (415) 476–4980 (Voice)
(415) 476–7600 (TDD)

PROJECT PERIOD: 03/88 – 02/93

SUMMARY:

The purpose of this long-term project is to develop, implement, and evaluate a social-cognitive group program to raise the levels of social functioning of deaf adolescents and adults. The program aims to compensate for gaps and losses in the developmental social experience of those deaf individuals who are low-functioning by a group program which provides opportunities for mediated learning in the social domain. In other words, group activities are selected and/or developed which structure opportunities to think (understand and reason) about people, about relationships, and about social events and issues in a guided way. We hypothesize that if a program of mediated intervention can raise levels of social cognition (perspective taking, person conceptualization, communication, and social causal reasoning and problem-solving), then improved social and socio-emotional functioning will follow. The project design includes phases for development, piloting, refinement, and evaluation of the program with groups of deaf adolescents enrolled in high school and with groups of deaf adults not enrolled in any regular program. The evaluation phase includes, initially, development of a rating measure of social functioning for use by teachers and counselors, and finally, an experimental design comparing matched treatment and control groups for changes related to participation in the social-cognitive group program.

TITLE: Assessment of Family–Community Fit

PRINCIPAL INVESTIGATOR:

Joan Patterson, Ph.D.
Center for Children with Chronic Illness
and Disability
Box 721 UMHC
Minneapolis, MN 55455

PHONE NUMBER: (612) 626–4032

PROJECT PERIOD: 1991 – 1994

SUMMARY:

This project will extend the development of a self-report instrument designed to assess the degree to which families with special needs children feel they "fit" into their community. To date, interviews with 75 families with special needs children have been conducted to determine the components of fitting in the community. Literature on psychological sense of community and family adaptation to stressors has been reviewed to further identify components of this fit. A set of questionnaire items have been generated and are ready to be field-tested with a large sample of families with the help of 90 professionals working with families of recruited special needs children. Responses of 1,000 parents will be factor analyzed to determine the principal components of family-community fit and scales with good reliability will be developed.

TITLE: Community Partners

PRINCIPAL INVESTIGATORS:

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Janet Williams, MSW
Beach Center on Families and Disability
3111 Haworth
The University of Kansas
Lawrence, KS 66045

PHONE NUMBER: (913) 864–7600

PROJECT PERIOD: 07/01/90 – 06/30/91

SUMMARY:

The Community Partners Program is developing, implementing, evaluating, and disseminating social network strategies for promoting three goals for young adults with severe disabilities: 1) Self-determination, 2) Supported/competitive employment, and 3) Independent living. People served by the program are individuals who have exited from high school education within the past five years and have encountered significant barriers to achieving self-determination and their chosen vocational and independent living outcomes. The Partners approach builds on the "Circle of Friends" model in developing Partners groups to provide social support. Other strategies that are incorporated into the Partners model include: cooperative learning, peer counseling, peer tutoring, citizen advocacy, and self-advocacy.

Currently, seven individuals were severe disabilities and their families are receiving services and support. This project has:

- Completed a comprehensive review of literature on groups for promoting program goals;
- Developed and implemented a naturalistic inquiry investigation to document the process, procedures, and outcomes of the Community Partners program;
- Prepared three 1½ hour teleworkshops to be disseminated to sites in approximately 25 states in the United States and Canada to describe the Community Partners model outline.

This project will:

- Develop, implement, and evaluate a training model to prepare community volunteers to serve as facilitators for new Partners groups;
- Serve an additional eight individuals with disabilities and their families with volunteer facilitators;
- Develop, implement, and evaluate a curriculum to increase the skills to individuals with severe disabilities in the area of self-determination;
- Prepare articles for peer-review journals and family newsletters and training manuals/video-tapes to disseminate results.

TITLE: Functional Competencies and their Relationship to Key Outcomes

PRINCIPAL INVESTIGATORS: Krista Kutash, M.B.A. and
Starr Silver, Ph.D.
Research and Training Center for Children's Mental Health
University of South Florida
Florida Mental Health Institute
13301 Bruce B. Downs Boulevard
Tampa, FL 33612

PHONE NUMBER: (813) 974–4500

PROJECT PERIOD: 09/27/89 – 09/28/94

SUMMARY:

This project will assess the empirical relationship between functional abilities and outcomes in a number of critical domains using data from the National Adolescent and Child Treatment Study. Analyses will center on the relative role of cognitive competencies, emotional competence, and adaptive competence, including social skills in predicting educational attainment, employment, living status, and social relationships.

TITLE: Improving Memory of EMR Children

PRINCIPAL INVESTIGATOR: Hilary Horn Ratner, Ph.D.
Wayne State University
Psychology Department
71 West Warren
Detroit, MI 48202

PHONE NUMBER: (313) 577–5244

PROJECT PERIOD: 07/01/87 – 10/31/89

SUMMARY:

This study's objective is to develop, for educable mentally retarded (EMR) children, instructional strategies that are embedded in a social context and will enhance children's memory performance across time and situation. Specifically, the project tests the use of a 12-week training program in which the subject children's memory skills will be exercised and developed through the use of demand conditions and self-generated memory strategies. With the accomplishment of this objective, it is hoped that EMR children will reach a more nearly normal level of functioning in society.

TITLE:	Networking Services for Adolescents with Sickle Cell Disease: An Interdisciplinary Demonstration Project
PRINCIPAL INVESTIGATOR:	Pearlie Fennell, Ph.D. Sickle Cell Disease Research Foundation of Texas, Inc. 2626 South Loop West, Suite 245 Houston, TX 77054
PHONE NUMBER:	(713) 666–0300
PROJECT PERIOD:	10/01/87 – 09/30/90

SUMMARY:

This project will develop a network of coordinated psychosocial community services designed to address the unmet psychosocial needs of adolescents with sickle cell disease and to assist these individuals in preparation for a productive adulthood. The program will focus on enhancing the self-concept and self-esteem of the adolescents enrolled in the program.

TITLE:	Normalizing the Social Behavior of Children with Autism
PRINCIPAL INVESTIGATOR:	Gail G. McGee, Ph.D. University of Massachusetts at Amherst Walden Learning Center Department of Psychology University of Massachusetts Amherst, MA 01003
PHONE NUMBER:	(413) 545–4791
PROJECT PERIOD:	10/01/88 – 09/30/91

SUMMARY:

The purpose of this project is to study the definition, assessment, and treatment of the severe social disabilities associated with autism. There are three concurrent and interactive research tracks. First, there are a series of studies of the ongoing probabilities of naturally-occurring social behaviors in a preschool setting, which contribute to the definition of the targets of social interventions, as well as to the evaluation of treatment outcomes. An inter-disciplinary team, representing divergent perspectives, is also providing input on the key differences in the social behaviors of children with autism and typical children. Finally, a series of studies is focused on interventions that address core autism deficits, and on examinations of incidental teaching process variables that promote generalized gains in social development. In sum, the goal of this project is to discover information that facilitates the long-term social integration of children with autism.

TITLE: Research and Training Center on Community Living: Enhancing the Social Networks of Persons with Mental Retardation

PRINCIPAL INVESTIGATORS:
Robert Bruininks, Ph.D.
David Johnson, Ph.D.
Martha Thurlow, M.A.
Brian Abery, Ph.D.
Research and Training Center on
Community Living
University of Minnesota
110 Pattee Hall
150 Pillsbury Avenue, S.E.
Minneapolis, MN 55455

PHONE NUMBER: (612) 625–4848

PROJECT PERIOD: Year 3

SUMMARY:

The initial phase of the project documents the current interpersonal contacts and friendships, and networks of adults with mental retardation who are residing in large and small residential facilities, living at home, or in foster care, and are involved in a variety of day-time activities ranging from competitive employment to day-programs. The second goal of the project is to develop and implement testable strategies to promote the development and maintenance of social relationships and supports of both a formal and informal nature. This phase of the project will be directed by the data collected and analyzed as part of the initial descriptive study and will focus on enriching the social networks of participants through the development and implementation of interventions designed to: (1) facilitate the development of social skills, (2) improve access to environmental contexts in which social interaction can naturally take place, and (3) enhance the quality of community services available to persons with mental retardation.

TITLE: Self-Advocacy Skill Building for Youth with Disabilities

PRINCIPAL INVESTIGATOR:

Robert Wm. Blum, M.D., M.P.H., Ph.D.
Center for Children with Chronic Illness and Disability
Box 721 UMHC
Minneapolis, MN 55455

PHONE NUMBER: (612) 626–4032

PROJECT PERIOD: 1991 – 1994

SUMMARY:

Audiovisual materials will be developed for youth with disabilities which are entertaining in content and are of benefit to them and their non-disabled peers in developing the skills of advocacy with the goal of full participation in decisions which govern their lives. The goal is that prototype materials can be developed which can form the basis of a grant application to federal agencies and private foundations.

This project would involve pre and early teens with chronic disabilities discussing problems and issues in their lives such as independence, socializing, forming relationships, sexuality, compliance with medical regimens and protocols, and coping with hospitalization. Taped interviews would then be shown to older teens with the same types of chronic illnesses to offer suggestions and answers and to share experiences and feelings.

The finished product would involve both sets of interviews and would be beneficial to chronically ill teenagers as well as their families and caregivers. Health professionals would also benefit from viewing the tape, as they would better understand the prevailing issues in the lives of these young people.

The primary goals of the program are to help adolescents with chronic disabilities learn important social skills and competencies related to their illness, channel the power of peer pressure in ways that reinforce young people in making responsible personal decisions, and to serve as a creative expression that will underscore the control and independence kids with chronic disabilities can have in their own lives.

TITLE: Social Competency Assessment

PRINCIPAL INVESTIGATOR: Scott McConnell, Ph.D.
Center for Children with Chronic
Illness and Disability
Box 721 UMHC
Minneapolis, MN 55455

PHONE NUMBER: (612) 626–4032

PROJECT PERIOD: 1990 – 1994

SUMMARY:

1. What are the age/developmental, social/contextual, family, and condition-related variables associated with social competence among children and youth with disabilities?
2. How does social competency vary among various environments within which the child with disabilities interacts?
3. What are the factors associated with social competence in various settings?

The goal of this study is to identify how competence is manifested in various environments and how those environments support or inhibit the competence of children with chronic illness or disability. Social competence, as one of the marker variables of children's psychosocial development in the above-mentioned longitudinal study, will be assessed in multiple settings—home, school, neighborhood, and hospital. Differences in social competence by setting will be examined and developmental, social, family, and condition-related predictors of competence will be identified.

This study is an integral part of Study #1 and, hence, planning has been concurrent. Research instruments have been selected and will be piloted as pat of the entire research protocol for Study #1. A subsample of #1 will be drawn after enrollment is completed (Year 3) so that assessment of social competence in one additional setting can be carried out.

TITLE: Social Networks

PRINCIPAL INVESTIGATOR: Brian Abery, Ph.D.
Center for Children with Chronic Illness
and Disability
Box 721 UMHC
Minneapolis, MN 55455

PHONE NUMBER: (612) 626–4032

PROJECT PERIOD: 1990 – 1994

SUMMARY:

The purpose of this research is to conduct quantitative and qualitative assessments of existing social and interpersonal networks, develop and implement individualized intervention strategies based on an ecosystems framework, and evaluate the effectiveness of those strategies for promoting interpersonal and social relationships for children with a variety of handicapping conditions, especially those who are severely handicapped, multiply handicapped, and/or are experiencing chronic illness.

The integration of children with disabilities into the mainstream of community life contributes to child development and competence. However, children with chronic conditions often experience barriers to developing and maintaining interpersonal contacts. In this project, the social networks of school-age children with disabilities will be studied: a) to identify child, family, and community barriers and resources to interpersonal contact in different settings; and b) to examine change in social networks over time and across transitions. Based on these descriptions, an intervention designed to promote network formation and interpersonal contact will be tested and evaluated in terms of improved psychological development and social adjustment.

The focus will be on youth networks. This will allow us to elicit more in-depth information with respect to the person's social network and, thus, more effectively plan the interventions to facilitate the enrichment of the network. Data on family networks will be conducted on a subsample of families who agree to participate in the Longitudinal Study. For the barriers analysis, we will conduct community forums only with families, including the person with disability since information about barriers from other community members has already been collected in other projects.

TITLE: Social Transition of Deaf Seniors

PRINCIPAL INVESTIGATOR: Randolph Mowry, Ph.D.
University of Arkansas, Rehabilitation
Research and Training Center on
Deafness and Hearing Impairment
4601 West Markham Street
Little Rock, AR 72205

PHONE NUMBER: (501) 371–1654 (V/TDD)

PROJECT PERIOD: 09/86 – 09/91

SUMMARY:

This study investigates the "social transition" of deaf high school students from high school to postsecondary or community settings. Social transition refers to the changes that occur in the social relationships of deaf students related to graduation, and how these social changes influence the student's psychological adjustment. Graduation involves significant changes in the graduate's roles, and responsibilities can be stressful. This stress occurs when the graduate's social networks are changing, reducing the resources of information and support for successful coping and possibly causing problems in adjustment.

This study documents the changes in the student's networks and social support, the degree of stress experienced, and adjustment. The results will be used to develop an intervention to help students recognize the upcoming changes, and provide them with techniques to manage the changes.

Two hundred deaf students in the mid- and south-west from residential and public school programs completed a questionnaire prior to graduation from high school that measured adjustment, social networks and support, and stress; 93 graduates completed the postgraduation questionnaire measuring the same variables. The two assessments permit documentation of changes the students have experienced.

TITLE: Survey of Chronically Ill Children's Use of Time Out of School

PRINCIPAL INVESTIGATOR: Bonnie Holaday, R.N., D.N.S.
University of California at San Francisco
Family Health Care Nursing
San Francisco, CA 94143

PHONE NUMBER: (415) 476–4663

PROJECT PERIOD: 04/01/87 – 03/31/90

SUMMARY:

The primary aim of this study is to describe and analyze the everyday out-of-school life experiences of chronically ill school-age children, and to examine the effects of different ecological contexts on the child's out-of-school life. Based on the analysis of data from a pilot study, two general hypotheses have been developed: (1) The patterns of chronically ill children's time use depend on the extent to and the manner in which parents and others engage in joint activities with them; and (2) the capacity of the parents to engage in such joint behavior depends on the extent to which there exist external support systems that provide opportunity, assistance, resources, and channels of communication.

Family

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TITLE: A Survey of Children in Alternative Care Settings

PRINCIPAL INVESTIGATOR: Peggy West
Center for Children with Chronic Illness and Disability
Box 721 UMHC
Minneapolis, MN 55455

PHONE NUMBER: (612) 626–4032

PROJECT PERIOD: 1989 – 1990

SUMMARY:

1. What are the social and emotional consequences to families who provide home care to children who are technology-dependent?
2. In families where there appears to be the capability to manage the demands of home care successfully, what factors contribute to the capability?

Since this longitudinal study of medically fragile children will become an additional comparison group for the core longitudinal study, all other efforts in specifying the protocol for this project have been incorporated into the core Longitudinal Study #1.

Undertake a mailed survey of 100 non-institutional, alternative residential facilities in the state of Washington to develop a profile of which children with chronic illnesses and disabilities reside in alternative facilities. In addition, the survey will provide information on the degree to which the providers of alternative care are aware of and maintain records on the disabilities (and related needs) of their residents.

This profile, useful in its own right, will be additionally beneficial in prospectively defining one component of the longitudinal sample (Study #1). Knowing the types of disabilities more likely to be represented among children in alternative facilities, we will be able to oversample for such conditions when we enroll subjects in the Longitudinal Study and thereby capture the natural unfolding of and the factors giving rise to this placement decision.

TITLE: An Evaluation of Family and LEA Decisions Regarding the Appropriate Placement of Children with Technology Support

PRINCIPAL INVESTIGATOR: Pat Barber, Ph.D.
Beach Center on Families and Disability
3111 Haworth
The University of Kansas
Lawrence, KS 66045

PHONE NUMBER: (913) 864–7600

PROJECT PERIOD: 07/01/90 – 06/30/91

SUMMARY:

As an increasing number of children supported by medical technology move from the confines of health care institutions to home and community settings, school systems and families are beginning to face the challenge of providing appropriate educational services to meet the unique needs of these students. Service provision as well as the appropriate integration of many of these children into educational settings will depend on the resolution of such issues as health care costs, liability, personnel training, assessment, and the coordination of health, education, family, and related service systems. Current educational and health policies provide minimal guidance in addressing these and other factors affecting placement and the provision of services. To date, there is limited information on how service and placement decisions are made for these students. This project has:

- Completed and disseminated an Annotated Bibliography and completed and disseminated a literature review on educational services to children who are chronically ill and technology-supported;
- Contacted or interviewed by telephone over 60 parents and professionals across the country who have experience working with children who are ventilator-assisted in order to gather information about the characteristics and service needs of these children and the educational services issues related to this population;
- Conducted pilot interviews with parents of children who are ventilator-assisted, physicians, and educators as a means of confirming and supplementing information on educational service issues reported in the literature and through telephone contacts.

This project will:

- Conduct research on the factors affecting educational placement and service decisions through surveys and interviews with families of children who are ventilator-assisted and LEAs serving these children in at least six states;
- Disseminate research results through the development of a research monograph, journal articles aimed at special educators, school administrators, and school health personnel, and a handbook of "how-to" articles on practical information for families who participate in educational decisions.

TITLE: Assessing Treatment Effectiveness and Family Empowerment

PRINCIPAL INVESTIGATOR:
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PROJECT PERIOD: 09/89 – 08/94

SUMMARY:

This research will study the effectiveness of an integrated system of mental health services for children and adolescents that is based on a family empowerment approach. The study has four components. Two in-depth followup interviews are being added to an ongoing evaluation of a major child and adolescent services demonstration at Ft. Bragg funded by the Department of Defense and the State of North Carolina. A randomized trial, nested within the evaluation, is exploring the effectiveness of a model of case management that focuses on building family strengths while insuring appropriate treatment for child clients. Through a subcontract to the North Carolina Department of Human Resources, research is under way to develop a reliable and valid measure of level of adaptive functioning by clients. Longitudinal course of childhood psychopathologies will be examined by using the extensive data base generated by the Ft. Bragg demonstration and evaluation.

TITLE: Assessment of Family–Community Fit

PRINCIPAL INVESTIGATOR:
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PHONE NUMBER: (612) 626–4032

PROJECT PERIOD: 1991 - 1994

SUMMARY:

This project will extend the development of a self-report instrument designed to assess the degree to which families with special needs children feel they "fit" into their community. To date, interviews with 75 families with special needs children have been conducted to determine the components of fitting in the community. Literature on psychological sense of community and family adaptation to stressors has been reviewed to further identify components of this fit. A set of questionnaire items have been generated and are ready to be field-tested with a large sample of families with the help of 90 professionals working with families of recruited special needs children. Responses of 1,000 parents will be factor analyzed to determine the principal components of family-community fit and scales with good reliability will be developed.

TITLE: Development of Respite Care Materials for Families With Children Who Have Disabilities

PRINCIPAL INVESTIGATOR: Mary Lou Licwinko
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PROJECT PERIOD: 08/15/89 – 08/15/91

SUMMARY:

The purpose of this project is to produce three products designed to educate families, care providers, and the public about the need for respite care for families who have children with multiple disabilities. CSR researched, developed, and field tested two guides on respite care. The first, *Respite Care: A Guide for Parents*, is an informational guide that addresses parent's guilt, fears, and other concerns about using respite care and provides information on how to locate respite care, pay for it, et cetera. The second, *Respite Care is for Families: A Guide to Program Development*, is designed to serve as a resource for individuals and organizations interested in starting respite care programs. This guide includes information on what parents are looking for in a respite care program, the various factors to address in setting up a program, and published information on respite care programs.

The third product being produced as part of this project is a 10 minute videotape on respite care and families that use it. The tape, currently in the production stage, focuses upon real families and their experiences with respite care. The videotape is designed to introduce and explain to those unfamiliar with the concept the benefits of and the need for respite care to families with children who are disabled or who have multiple health care needs.

TITLE: Families and Communities in Transition

PRINCIPAL INVESTIGATOR: Kathy Schwaninger
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PROJECT PERIOD: 07/01/87 – 06/30/90

SUMMARY:

The purpose of this project is to encourage and expand home care as an option for families of children with special health needs. Objectives include empowering families who choose home care with the necessary skills and knowledge to become their own effective case managers; creating a collaborative system between parents and professionals in planning and caring for children; and improving and expanding both current home health and other community service provisions for children and their families.

TITLE: Families As Allies

PRINCIPAL INVESTIGATOR: Neal DeChillo, D.S.W.
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Regional Research Institute for Human Services
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Portland, OR 97207–0751

PHONE NUMBER: (503) 725–4040

PROJECT PERIOD: 10/01/89 – 09/30/94

SUMMARY:

The Families as Allies Project builds on the accomplishments of the previous five years by testing the effectiveness of the collaboration training curriculum developed by the Portland Research and Training Center. The evaluation will use as experimental design and will include professionals and family members. The professional sample includes workers from mental health, child welfare, and special education. A unique feature of the study is the assessment of collaboration from the perspectives of both family members and professionals. Additional measures include the assessment of attitudes and behaviors relating to collaboration before and after training. Three and six month follow-ups will also be conducted to examine the relationship of collaboration to multi-dimensional outcome measures.

In addition to the empirical assessment of the model training curriculum the project is also: (1) collecting data on different aspects of collaboration in order to develop and refine an instrument for measuring this construct; (2) providing consultation and technical assistance to the existing national network of parent-professional trainees; (3) updating and refining an annotated bibliography on parent-professional collaboration; (4) refining the training handbook for parent-professionals; and (5) disseminating project materials, including research findings, to family and professional audiences.

TITLE: Families Caring for Medically Fragile Children at Home

PRINCIPAL INVESTIGATOR/ PROJECT DIRECTOR:

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Joan Patterson, Ph.D.
Center for Children with Chronic Illness and Disability
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PHONE NUMBER: (612) 626–4032

PROJECT PERIOD: 1990 – 1994

SUMMARY:

An extant data set comprised of a time one survey and a two-year follow-up survey of a sample of 45 families who have a medically fragile child living at home will be analyzed. The analyses will focus on identifying: a) Unique hardships of home care which call for further support programs and policy analysis; and b) factors associated with families' ability to successfully manage these more complex care needs of technology-dependent children.

Given our intention to include a subsample of medically fragile children in the Longitudinal Study, these analyses will further inform our selection of variables to be assessed. In addition, this is a relatively new and growing population of children and there is a paucity of information on the long-term impact to children, parents, and families of providing high tech care at home. Given the presence of professionals assisting the family in providing care at home, these analyses will increase our understanding of factors associated with more effective parent-professional collaboration.

TITLE: Family-Centered, Community-Based Project

PRINCIPAL INVESTIGATOR: Sandra J. Mathes
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PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

This project addresses the need to establish a regionalized system of community-based service centers to assist the families of children with special health care needs in coordinating and obtaining access to needed services. Strategies include instituting a multidisciplinary team to ensure coordination and service delivery through support of case planning, case management, referrals, and education of the client population and general public; and developing linkages between community service providers and the centrally located, more fully developed resources in Little Rock.

TITLE: Family-Centered, Community-Based Services for Children with Cancer

PRINCIPAL INVESTIGATOR: Beverly J. Lange, M.D.
Children's Hospital of Philadelphia
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Philadelphia, PA 19104

PHONE NUMBER: (215) 590–2249

PROJECT PERIOD: 10/01/88 – 09/30/91

SUMMARY:

Traditionally, treatment of pediatric cancer has required high-technology, provider-intense care, which is expensive and disrupts family life and the child's socialization and education. The goal of this project is to design alternative means of treatment by: (1) Moving the delivery of some high-technology care for children with cancer from a Level III hospital to the community and home; (2) providing community-based intervention for those children at risk for learning disabilities caused by cancer or its treatment; and (3) developing a community-based system of followup services for long-term survivors.

TITLE: Family Definitions of Health and Disability: Ethnoracial Variation

PRINCIPAL INVESTIGATOR: Joan Patterson, Ph.D.
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Box 721 UMHC
Minneapolis, MN 55455

PHONE NUMBER: (612) 626–4032

PROJECT PERIOD: 1991 - 1993

SUMMARY:

1. How are health, disability, and illness defined by various cultural groups?
2. What are the intercorrelations between cultural definitions, family definitions, and self-perception of children with chronic illnesses and disabilities?
3. How do these definitions change across time (e.g., as the child changes developmentally and/or the exigencies of the conditions change) and what are the consequences of changing perceptions?
4. What attitudes and meanings are developed by families about their child's illness/disability and how do these shape the process of adaptation and influence child and family outcomes?
5. To what extent does family orientation (e.g., to the sick or disabled child vs. to a family who has a member with a disabling condition) predict different adaptational outcomes?

This study will focus on the identifying variation within and across racial and ethnic groups regarding: a) the subjective meanings families assign to their children's health and disability; and b) how these meanings affect their willingness to access health and education services. The sample for this cross-sectional qualitative study will consist of 15 families of children with a physical disability (e.g., spina bifida or cerebral palsy in each of three ethnoracial groups: African-America, Hispanic, non-Hispanic white. The children studies will be between the ages of birth–2 years and 8–10 years. This study, to be conducted in Year 3, will recruit participants from a sample already identified in the study of *Needs of Families of Color #9* and will build upon the findings from that study. Other participants will be recruited from the Longitudinal Study and other sources. In order to clearly describe both disability and ethnoracial issues, a comparison group of families without a disability will be recruited by asking the study families to suggest a family of their acquaintance of the same ethnoracial heritage with a similar-age child without a disability. Semi-structured, in-depth interviews will be conducted with these 90 families based, in part, on the focus group findings but will most likely emphasize those variables originally proposed: attributions regarding the causes and responsibilities for the disability; implicit and found meanings regarding health, disability, and illness; health locus of control; family schema or world view dimensions; and cognitive coping strategies. These variables, then, will be linked to the families' perceptions of need for, and utilization of, services.

TITLE:	Families in Action
PRINCIPAL INVESTIGATOR:	Nancy Koroloff, Ph.D. Research and Training Center on Family Support and Children's Mental Health Regional Research Institute for Human Services Portland State University P.O. Box 751 Portland, OR 97207–0751
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PROJECT PERIOD:	10/01/89 – 09/30/94

SUMMARY:

The Families in Action Project is developing and testing strategies that will encourage the involvement of family members in policy and decision-making processes affecting services for children with emotional disabilities. The project focuses on parent participation in community-based services at the community and state level. The project involves a three-phase process.

Phase I is an extensive literature review on citizen and consumer participation and structured data collection from selected family members and professionals active in state and community level decision-making processes. This information is being used to refine conceptual models and strategies for effective family participation. Phase II is the development of strategies for working with family members and professionals in selected demonstration sites. Project staff will work with individuals in the demonstration sites to identify opportunities for participation both by project staff and family members. Plans will be developed to facilitate family involvement in the identified opportunity. This plan may include training and technical assistance as well as other approaches. Phase III includes an evaluation of the strategies employed by both project staff and parents and each strategy's general applicability.

TITLE: Family Caregiver Survey

PRINCIPAL INVESTIGATOR: Tom McDonald, Ph.D.
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Regional Research Institute for Human Services
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PHONE NUMBER: (503) 725–4040

PROJECT PERIOD: 10/01/89 – 09/30/94

SUMMARY:

The Family Caregiver Survey Project is developing a comprehensive model of family caregiving for families of children and youth with a serious emotional disability. The model to be tested ultimately seeks to identify the determinants of family functioning, child well-being, and caregiver well-being in these families. In doing so, the project is considering a range of factors, some of which are given characteristics of the family, child, or community (e.g., sex of the child, marital status of caregiver, and population density), and other changeable characteristics that may vary as families attempt to deal with their child's disability (e.g., perceptions of disability, availability and use of community services).

The identification of both given and changeable characteristics that affect these families and their children are important for administrators, practitioners, family advocates and the families themselves. The given characteristics can be used to identify unmet needs and for targeting special intervention efforts. Changeable characteristics can be manipulated to maximize positive outcomes for these families and children. In this way it is expected that the development and testing of a comprehensive family caregiving model can contribute to the well-being of children with severe emotional disabilities and their families.

TITLE:	Family Coping Strategies and Their Relation to Rehabilitation Outcomes Among Young Adults With Mental Illness
PRINCIPAL INVESTIGATOR:	Mardi Solomon, Ph.D. Thresholds Research Institute 561 Diversey Parkway, Suite 210A Chicago, IL 60614
PHONE NUMBER:	(312) 348-5522
PROJECT PERIOD:	09/30/90 – 09/29/95

SUMMARY:

The purpose of the proposed research project is to compare the degree of burden experienced by parents of severely mentally ill offspring with the degree of burden reported by a group of parents of same-aged offspring who are not mentally ill and who reside in the same geographic and socio-economic neighborhoods of Chicago, Illinois. This will be done to address several questions regarding both objective aspects of familial burden such as strain on family finances and deterioration of social support networks, and subjective aspects of burden such as feelings of depression and anxiety, as well as their relation to ill offsprings' rehabilitation outcomes. First, affected parents' self-esteem, coping mastery and morale will be compared to levels found among parents of "normal" offspring. Second, the attitudes of affected parents toward the mental health professions will be compared with those of the non-affected group of parents. Third, affected parents' experiences with a series of problems identified in the literature on parental burden among family caretakers will be compared to many parents of "normal" children. Fourth, the levels of physical and emotional symptomatology experienced by affected parents will be compared with levels reported by parents of non-disabled offspring. Finally, parents' degree of burden will be correlated with their offsprings' eventual rehabilitation outcomes in the residential, vocational, and recidivism areas. At present, data addressing these questions from 222 parents of mentally ill offspring entering a psychiatric rehabilitation program have been collected, coded, and entered in the computer. The task at hand at present, then, is to collect the same information from a group of parents of adult offspring who are not afflicted with psychiatric disability. A community college on the North side of Chicago has agreed to allow its Alumni Association to supply names and addresses of target age parents as well as an endorsement of the project and its aims. Alumni parents will then complete the study instruments and return them by mail. This will allow matching parents of similar age offspring, from similar areas of Chicago, and at similar educational levels.

TITLE: Family-Friendly Methods of Identifying Family Strengths and Needs and Developing Individualized Family Service Plans (IFSP)

PRINCIPAL INVESTIGATOR: Jean Ann Summers, Ph.D.
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The University of Kansas
Lawrence, KS 66045

PHONE NUMBER: (913) 864–7600

PROJECT PERIOD: 07/01/90 – 06/30/91

SUMMARY:

Public Law 99-457 specified the development of Individualized Family Service Plans (IFSPs) to enhance the capacity of families to support young children with special needs. Other developing policies, such as state initiatives to develop transition plans for students leaving special education and entering adult services point toward the need to develop comprehensive, individualized family support plans that are relevant across the life cycle. Unfortunately, most previously client- or service-centered programs are at a loss to know how to incorporate family needs and strengths into their planning for services. This study has identified family preferences with respect to these issues and is investigating the efficacy of a family-responsive IFSP development process. The study will have immediate impact of early intervention programs and state Part H agencies that are struggling to implement family-responsive services. This project has:

- Completed a focus-group study to identify family preferences with respect to the development of the IFSP in early intervention;
- Completed a focus-group study with families and providers concerning preferences with respect to developing individualized transition plans from special education to adult services;
- Consulted with State Agency Part H programs on development of family-focused IFSPs in early intervention in 3 states;
- Conducted workshops on family-friendly approaches to developing IFSPs, in 1989–90, to more than 600 family members and early intervention providers in 10 states.

This project will:

- Evaluate the effectiveness of the model IFSP process in early intervention sites;
- Develop and field-test a program evaluation rating scale for early intervention programs based on family preferences for services;
- Program training to all regional case managers in the state of Missouri; consult with the state of Kansas; and continue dissemination.

TITLE: Family Perceptions Project

PRINCIPAL INVESTIGATOR: Jean Ann Summers, Ph.D.
Kansas University Affiliated Program
Bureau of Child Research
University of Kansas
Lawrence, KS 66045

PHONE NUMBER: (913) 864-4950

PROJECT PERIOD: Project completed 09/14/90

SUMMARY:

Research suggests that families' perceptions of their children with disabilities have a strong relationship to their ability to cope with the challenges of raising their child. The purpose of this study was to develop and validate measures of the use of four specific coping strategies suggested by cognitive adaptation theory: identifying a cause of the disability, perceiving positive benefits of the child, making comparisons with others, and having a sense of mastery or control of the situation. Measures were developed and field tested with 300 parents of children with and without disabilities. These results were factor analyzed and the revised, shorter instruments were completed by a sample of 1,262 parents of children with disabilities in 34 states.

The results suggest that three of the four instruments (positive contributions, social comparisons, and causal attributions) are internally consistent and show correlations in the expected directions between selected factors on the instruments and parents' feelings of stress and self-esteem. The mastery questionnaire showed results opposite the expected direction (high positive correlations of personal control with stress); follow-up interviews with a sample of respondents suggest this instrument may have been tapping a different construct (sense of responsibility, rather than sense of control). Data are currently being analyzed to identify differences in responses among families of younger and older children, levels of severity of the child's disability, and mothers versus fathers. Future research will focus on continuing the revision and validation of these instruments, measuring and comparing professional perceptions of parents' cognitive coping strategies, and developing interventions to teach families effective use of these coping strategies.

TITLE: Family Reorganization

PRINCIPAL INVESTIGATOR: Joan Patterson, Ph.D.
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Box 721 UMHC
Minneapolis, MN 55455

PHONE NUMBER: (612) 626–4032

PROJECT PERIOD: 1991 – 1994

SUMMARY:

1. How does the family reorganize itself following diagnosis or onset of the condition so as to incorporate the demands of the illness/disability into family life (while still attending to other family needs) and restore balanced functioning to the family system?
2. How does the family reorganize itself at critical developmental transitions to facilitate age-appropriate levels of independence and self-care in the disabled child or adolescent?
3. What are the factors associated with social competence in various settings?

The diagnosis of chronic illness or disability disrupts normal family processes. In this study, qualitative methods (home observations and laboratory tasks) will be used to describe how families reorganize their internal structure to successfully manage the cognitive, behavioral, and emotional tasks associated with the chronic illness or disability while simultaneously meeting the needs of all family members. Families will be studied at the time of diagnosis and at other critical developmental milestones when reorganization is called for. These findings will contribute to better programs and interventions designed to support successful child and family adaptation.

TITLE:	Family Support Groups: Factors Influencing Leadership, Participation, and Member Change Among Relatives
PRINCIPAL INVESTIGATOR:	Judith Cook, Ph.D. Thresholds Research Institute 561 Diversey Parkway, Suite 210A Chicago, IL 60614
PHONE NUMBER:	(312) 348–5522
PROJECT PERIOD:	09/30/90 – 09/29/95

SUMMARY:

Since deinstitutionalization, families have increasingly assumed responsibility for the care of their psychiatrically disabled relatives by providing housing, financial aid, social supports, and even case management services (Grella and Grusky, 1989). The reported number of families who care for relatives with mental illness varies greatly, but studies estimate that from 25% to 65% of deinstitutionalized patients return to their families for some sort of care. Families who assume the role of caregiver for relatives with mental illness face overwhelming psychological and economic burdens. Many families have reported high levels of stress due to disruptions in family routines, unpredictable, bizarre, and often destructive behavior, as well as crisis situations that arise when a person with mental illness lives in the home. This stress often appears in the form of significant increases in levels of anxiety, frustration, worry, sense of burden, depression, grief, fear, and anger. Studies of family service needs find that families require assistance in times of crisis and in coping with anxiety that develops when dealing with a psychiatrically disabled relative over time. Family support groups, which have become widespread in the past 15 years, have been an effective resource for families to obtain this much needed support, education, and information about handling crises. While many studies have addressed the reason why families attend support groups, there is a dearth of information about the actual changes that occur in group members as a result of group participation. Moreover, the styles and processes of these groups, and the ways in which they effect positive outcomes, have not been well researched. Therefore, the purposes of this proposal are to study the changes that occur in family members as a result of their participation in support groups, and to examine the structure and processes of these groups and their leaders in order to obtain an understanding of how these effect change in group participants.

TITLE:	Family Support Programs
PRINCIPAL INVESTIGATOR:	H. Rutherford Turnbull III Beach Center on Families and Disability 3111 Haworth The University of Kansas Lawrence, KS 66045
PHONE NUMBER:	(913) 864–7600
PROJECT PERIOD:	07/01/90 – 06/30/91

SUMMARY:

Although many states and local service providers operate family support programs, there have been only a few evaluations of the effectiveness of those programs. Significantly, none of the evaluations have been from the perspective of the families receiving family support services. Thus, no state or local operator can be sure concerning the effect of those programs on families and thus how to improve the programs. This research project evaluates family support programs from families' perspectives, based on the articulation goals, strategies, and underlying principles of the program.

This project will:

- Identify family support projects to be evaluated;
- Evaluate them from the perspectives of the families receiving services and on the basis of the articulated goals, strategies, and underlying values of the programs themselves;
- Conduct a thorough review and analysis of evaluation literature on family support;
- Prepare a report of the research/evaluation and a critique and analysis of the other evaluation literature; on the basis of the report, propose methods for improving family support programs;
- Disseminate the report and proposals for program improvement to the profession via peer-reviewed articles, to state and local providers (and to their national organizations) via direct mailing, and to the family-disability audience via families' organizations.

TITLE: Family Support Project

PRINCIPAL INVESTIGATORS: Nancy Fire, R.N., M.S.
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Oklahoma City, OK 73152

PHONE NUMBER: (405) 271-4471

PROJECT PERIOD: 07/01/87 – 06/30/90

SUMMARY:

This project seeks to increase support to children with special health needs by addressing the lack of formal support due to fragmentary services in local communities and the lack of identification and utilization of informal support. Project objectives are to: (1) Facilitate local community groups to address formal support system services needs; (2) enable volunteer parents to visit other families in their communities, thereby enhancing informal support systems; and (3) establish a grassroots network of families and community groups across the State.

TITLE: Model Family-Professional Partnership Interventions

PRINCIPAL INVESTIGATOR: Betty Pieper, R.N., B.S.
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PHONE NUMBER: (518) 459–7911

PROJECT PERIOD: 10/01/89 – 09/30/90

SUMMARY:

"Model Family-Professional Partnership Interventions for Childhood Traumatic Brain Injury Survivors," has been awarded funding by NIDRR for three years, October 1, 1988 to September 30, 1991. The following tasks have been completed to date:

a) reanalysis of existing survey findings for application to the present project;

b) evaluation of various instruments in preparation for the design of a caregiver questionnaire which assesses family stressors, coping and functioning in families with a childhood TBI survivor; the questionnaire was mailed in February 1990, and had a 60% response rate;

c) analysis of data from the questionnaire survey; preliminary data has been shared by Dr. Wayne Gordon of Mt. Sinai with the NYSHIA Pediatric Advisory Council on October 9, 1990;

d) review of the literature on interventions which rely on family-professional partnerships in developmental disabilities;

e) documentation of family perceptions of stressors and coping strategies after traumatic brain injury through a Nominal Process Group involving eleven selected families held in October 1989.

Tasks in process:

a) evaluation of the results of the Nominal Group Process by Dr. George Singer of the Oregon Research Institute; the results will be studied by selected professionals who are experts in the TBI service sector and these professionals will meet together in a Consensus Group on November 9, 1990 in order to establish priority interventions;

b) presentation of survey research results (quantitative component) by Wayne Gordon, Ph.D. will be presented on November 9, 1990 to the Consensus Group;

c) development of training materials and dissemination of findings.

TITLE: National Center for Family-Centered Care

PRINCIPAL INVESTIGATOR: Beverly H. Johnson
Association for the Care of Children's Health
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Bethesda, MD 20814

PHONE NUMBER: (301) 654–6549

PROJECT PERIOD: 07/01/89 – 06/30/94

SUMMARY:

The goals of the National Center for Family-Centered Care are to promote implementation of a family-centered approach to care for children with special health care needs; to foster parent-professional collaboration at all levels of health care; and to document the effectiveness of a family-centered approach to care for children with special health care needs.

TITLE: National Clearinghouse on Family Support and Children's Mental Health

PRINCIPAL INVESTIGATOR: Marilyn McManus, J.D., M.S.W.
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PHONE NUMBER: (503) 725–4040

PROJECT PERIOD: 10/01/89 – 09/30/94

SUMMARY:

The National Clearinghouse on Family Support and Children's Mental Health is the first clearinghouse designed to serve families of children with serious emotional disorders as well as professionals, policy-makers and other interested persons. It includes a national toll-free telephone service (800–628-1696), a computerized data bank, a series of fact sheets on issues pertaining to children who have emotional disabilities and their families, a state-by-state resource file, and the addition of a family resource coordinator to the Center's staff.

Available fact sheets address the following topics: children's mental, emotional, and behavioral disabilities; resources (books, journals, newsletters, and films) addressing children's mental health issues; starting parent/family support groups; financing; early intervention services; and descriptions of specific children's emotional disabilities including childhood depression, attention deficit hyperactivity disorder, and childhood schizophrenia.

TITLE: Program of Family-Directed Case Management

PRINCIPAL INVESTIGATOR: Carol R. Hassler, M.D.
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Handicapped Children's Services
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PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

The goal of this project is to increase the family-centeredness of care for children with special health needs by empowering families with the knowledge and skills they need to become case managers for their children. Program strategies include: (1) Restructuring service delivery models within Handicapped Children's Services; (2) training staff in the process of family-centered case management by parents; (3) fortifying interagency coalitions; (4) developing a philosophy statement for Vermont children with special health needs that reflects a commitment to support families and community-based care; and (5) defining and implementing the case management process.

TITLE: Psychosocial and Family Outcomes of Injured Children and Adolescents

PRINCIPAL INVESTIGATOR: Donald Wertlieb, Ph.D.
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PROJECT PERIOD: 01/01/88 – 12/31/92

SUMMARY:

Rehabilitation services for childhood trauma include a broad array of child and family interventions to enhance the recovery process. Rehabilitation programs are not complete, nor are they likely to be effective if the negative psychosocial impact of injury on children and families is not adequately addressed. The major goal of this project is to understand the nature and extent of child and family psychosocial problems after traumatic injury. Contributing clinical sites are the Kiwanis Pediatric Trauma Institute at Floating Hospital for Infants and Children, Boston, MA. A battery of measures assess child and family psychosocial status as well as school reintegration status at one month and again at six month post discharge. The measures include the Child Behavior Checklist, the Impact of Family Scale and School Reintegration Checklist. At the six-month follow-up, an additional measure is introduced with a Teacher Questionnaire to assess school behavior and academic performance. Outcomes of this project will include: 1) the description and frequency of child behavior problems, family disruption and stress, and school reintegration problems after injury, 2) the differential pattern of injury related psychosocial and school problems across varying trauma severity levels, and 3) the extent of recovery of behavior, psychosocial and school problems for injured children over a six-month periods, and how psychosocial factors relate to injury recovery.

TITLE: Reasonable Efforts in Permancy Planning

PRINCIPAL INVESTIGATOR: Christopher Petr, Ph.D.
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PHONE NUMBER: (913) 864–7600

PROJECT PERIOD: 07/01/90 – 06/30/91

SUMMARY:

Children with disabilities often seem to be high risks for out-of-home placement. This project will develop a state-of-the-art definition of "reasonable efforts" to maintain children with emotional disorders (ED), developmental disabilities (DD), and technology support (TS) in permanent placements in the least restrictive environment. The overall research question is: What state policies, programs, supports, and values regarding "reasonable efforts" are the most conducive to maintaining those children with emotional disorders, developmental disabilities, and technology support in the least restrictive, most home-like environments?

To answer this question, we will investigate two aspects of this issue during the first two years of the project. The first involves a policy analysis of one exemplary state's current "reasonable efforts." The second centers on understanding the stresses faced by families and the match between their needs and the same state's "reasonable efforts."

This project has:

- Begun data collection and analysis.

This project will:

- Complete data collection and analysis;
- Initiate educational and other change efforts to achieve implementation of the state-of-the-art definition of "reasonable efforts" in one or two targeted states;
- Work with family organizations, service providers, and policy makers;
- Submit the policy analysis for publication in a peer-reviewed journal;
- Prepare a manual on change efforts for family organizations;
- Present the content of the manual at annual meetings of family and provider organizations.

TITLE: Research on Teaching Cognitive Coping Strategies to Families

PRINCIPAL INVESTIGATOR: Shirley K. Behr, Ph.D.
Beach Center on Families and Disability
3111 Haworth
The University of Kansas
Lawrence, KS 66045

PHONE NUMBER: (913) 864–7600

PROJECT PERIOD: 07/01/90 – 06/30/91

SUMMARY:

Families play a major role in achieving national disability policy objectives which reflect the belief that family and community life is preferable to institutional life. The 1986 amendments to the Education of the Handicapped Act (P.L. 99-457, Part H, Sec. 672 [A]) requires professional support and intervention to strengthen families in their efforts to raise their children with disabilities at home and in the community. Building on theory and current research on cognitive adaptation, this project will examine the effectiveness of an intervention designed to strengthen families. The intervention will be delivered through workshops designed to teach families the use of cognitive coping strategies that are associated with enhanced family well-being. This project has:

- Completed a review of the literature on intervention approaches and published an annotated bibliography;
- Conducted group interviews with parents of individuals on their use of cognitive coping strategies, and obtained their feedback on the design of the workshops;
- Examined the relationships of specific coping strategies to family well-being through post-hoc analyses of data generated from a national study on cognitive coping strategies, conducted among 1,262 parents of individuals with disabilities, under a NIDRR funded field-initiated research grant;
- Developed the workshop components and materials for instructional activities, based on the results of the above analyses, and conducted a pre-pilot test of one workshop component preliminary to field-testing;
- Conducted a training workshop for professionals and made five presentations at national conferences for both family member and professional participants.

This project will:

- Field-test all intervention components, revise materials, and conduct workshops using an experimental and control group research design to examine the effectiveness of the intervention.
- Produce a manual of teaching materials for dissemination to family organizations and service providers.

TITLE: Siblings of Children with Disabilities

PRINCIPAL INVESTIGATOR: Barbara Leonard, Ph.D.
Center for Children with Chronic Illness
and Disability
Box 721 UMHC
Minneapolis, MN 55455

PHONE NUMBER: (612) 626–4032

PROJECT PERIOD: 1991 – 1994

SUMMARY:

Siblings will be studied concurrently to determine their psychosocial adjustment to living in a family with a chronically ill child. All siblings between the ages of 6 months and 21 years will be followed using the same measurement tools as those in the Longitudinal Study. Interviews with parents and siblings will be included. Our past research with siblings of medically fragile children and children with diabetes, epilepsy, cancer, and cystic fibrosis indicate a 3–5 fold increase in behavior problems over a normal population of children. The present study will provide a unique opportunity to examine family factors as well as those specific to children (age, sex, birth order) which contribute to their adjustment over time. Because no longitudinal data on siblings or chronically ill children is currently available, the findings from this study could be a significant contribution to the fields of family social science and child development.

TITLE: Specialized Family ER Program with Suicide Attempters

PRINCIPAL INVESTIGATOR: Mary J. Rotheram-Borus, Ph.D.
Research Foundation for Mental Hygiene
722 West 168 Street
New York, NY 10032

PHONE NUMBER: (212) 740–7323

PROJECT PERIOD: 09/90 – 08/95

SUMMARY:

Since family factors are of critical importance in understanding adolescent suicide attempts and are also important determinants of compliance with recommended treatment, Dr. Borus will be evaluating the effectiveness of a specialized emergency room (ER) family intervention for a consecutive series of 200 female suicide attempters aged 12–18 who are predominantly Black and Hispanic. Female suicide attempters will receive either standard ER care plus brief family therapy or a specialized ER program and brief family therapy. The specialized program will include: 90 minute crisis family intervention; a brief videotape about what families can expect therapy in therapy; training for staff in the ER, child psychiatry, and adult psychiatry on adolescent suicidality. Number of suicide reattempts and suicide-related risk factors will be assessed at 3, 6, 12, and 18 months.

TITLE: Supporting Families: A Strengths Model

PRINCIPAL INVESTIGATOR: John Poertner, D.S.W.
Research and Training Center on Family Support and Children's Mental Health
Regional Research Institute for Human Services
Portland State University
P.O. Box 751
Portland, OR 97207–0751

PHONE NUMBER: (503) 725–4040

PROJECT PERIOD: 10/01/89 – 09/30/94

SUMMARY:

The focus of the project is the evaluation of the Family Advocacy Model with families of Head Start children who have been identified as having mental health needs. This project helps families identify their strengths and needs, and locate and obtain services through a specialized case management approach. The hypotheses are that as a result of participating in the Family Advocacy Project caregivers will increase their ability to: recognize their caregiving strengths; recognize their child's strengths; recognize the child's special caregiving demands; increase their knowledge of strategies to meet the child's special needs; increase their ability to acquire educational services to meet the child's special needs; and increase their social supports as well as use of concrete services.

The evaluation is designed to determine the impact of the Family Advocacy Model on both caregivers and children served. This will be accomplished through a quasi-experimental design that will permit in-program and post-program comparisons of families and children receiving the services of the Family Advocacy Model with a cohort of similar families and children identified in the system in the year prior to implementation of the Family Advocacy Model.

TITLE:	Survey of Health Care Utilization and Family Out-of-Pockets Expenses
PRINCIPAL INVESTIGATORS:	Paul Newacheck, M.P.P. Peggy McManus, M.H.S. Center for Children with Chronic Illness and Illness Box 721 UMHC Minneapolis, MN 55455
PHONE NUMBER:	(612) 626–4032
PROJECT PERIOD:	1991 – 1994

SUMMARY:

This component of the longitudinal study is designed to provide new information on the costs incurred by families in caring for a chronically ill child. Through a mail-out survey of over 500 families conducted at regular intervals, the project will collect information on direct costs such as out-of-pocket expenses for hospital care, and indirect costs such as the value of lost parental employment opportunities. In addition, information will be collected on utilization of a range of health services by chronically ill children. These data will permit us to draw a relatively complete profile of the utilization and expenditure patterns for a fairly large sample of chronically ill children.

The project will also collect information on health insurance coverage. This information will be used to assess how health insurance influences use of services and family out-of-pocket expenses. Included also will be survey questions concerning perceptions of financial and insurance barriers to receiving needed health care services designed to elicit degree of worry or concern about health care bills. The goal of the project is to establish a database that can be used to address several key public policy issues, including:

Health Care Utilization Patterns

1. What services do chronically ill children use?
2. How does service use vary by age, severity, and diagnosis?
3. How do utilization patterns of chronically ill children compare to those of children without chronic conditions?

Direct Costs of Caring for Chronically Ill Children

1. What is the range of family out-of-pocket expenses for caring for a chronically ill child?
2. How do these expenditures vary by age, severity, and diagnosis?
3. How many families experience out-of-pocket expenses in excess of 5, 10, or 15 percent of their family income over the course of the year?
4. Which types of health care services lead to high out-of-pocket expenses?

TITLE: The Beach Center on Families and Disability

PRINCIPAL INVESTIGATORS: Ann Turnbull, Ed.D.
H. Rutherford Turnbull III
Beach Center on Families and Disability
3111 Haworth
The University of Kansas
Lawrence, KS 66045

PHONE NUMBER: (913) 864–7600

PROJECT PERIOD: 07/01/90 – 06/30/91

SUMMARY:

Established in 1988, the Beach Center on Families and Disability is the only federally funded research and training center in the nation with an exclusive focus on families with members with disabilities. The Center is involved in a wide range of research, dissemination, and training projects addressing family well-being across the lifespan. Currently, Center projects concentrate on families of persons with developmental disabilities and emotional disabilities, and technology support.

The work of the Beach Center is guided by six fundamental beliefs about families: Persons with disabilities make positive contributions to their families and society; families need to have great expectations so that visions can become realities; persons with disabilities and their families are entitled to full citizenship and to meaningful choices; strong relationships with each other and with friends in the community are crucial to family unity; and, while families often need support, we should be cognizant of the inherent strengths of most families.

The Center is currently conducting nine research studies and is committed to putting research results into practice for the benefit of families across the country who have members with disability. To that end, it is involved in a wide variety of dissemination and training activities directed at families and the professionals who serve them. They include interactive teleworkshops, a newsletter, the organization of conferences on specific issues of concern to families, training workshops, presentations at family and professional meetings, journal articles, manuals, books, and resource guides.

TITLE: The Family Enhancement Project: A Multicomponent Family Program

PRINCIPAL INVESTIGATORS:
Jan Sheldon, Ph.D.
James Sherman, Ph.D.
Beach Center on Families and Disabilities
3111 Haworth
Lawrence, KS 66045

PHONE NUMBER: (913) 864–7600

PROJECT PERIOD: 07/01/90 – 06/30/91

SUMMARY:

Adolescents with severe emotional disabilities often are at risk for out-of-home placement. To reduce those placements, consistent with the preference of public policy, families—not just the adolescent—need interventions that are effective, multi-faceted, tailored to families' self-identified needs, consented to and carried out by the families in cooperation with professionals, otherwise, the risk of out-of-home placement does not diminish sufficiently. This research investigates how to provide that kind of intervention to families. This project has:

- Nearly completed a massive review and analysis of the literature on family-based interventions for adolescents with severe emotional disabilities;
- Drafted two reviews and critiques of the literature for publication in peer-reviewed journals;
- Drafted manuals for families so that they will know how to participate most effectively (be "smart consumers") in home-based interventions;
- Provided intervention research and services for families and assisted in preventing out-of-home placements for all but one of the ten participating families;
- Established liaison with local mental-health agencies and local child-welfare and through the liaison provided technical assistance to those agencies;
- Established liaison with the local juvenile court system and provided technical assistance and consultation to the system;
- Applied the intervention techniques to families with adolescents and young adults with other disabilities (developmental disabilities).

This project will:

- Complete, by November 1990, the reviews, analyses, and manuals identified above;
- Disseminate them to professional audiences via peer-reviewed journals and to families via the national networks of families and their organizations and continue family-centered research.

TITLE: Alabama's Care Management Project

PRINCIPAL INVESTIGATORS: Glenna Graverson, Chris Beaird
Alabama State Department of Education
Division of Rehabilitation and Crippled
Children's Services
2129 East South Boulevard
Montgomery, AL 36111

PHONE NUMBER: (205) 792–0022

PROJECT PERIOD: 10/01/88 – 09/30/91

SUMMARY:

This project trains parents of older handicapped children to facilitate case management services to parents of special needs children by serving as "partners" to those parents and children eligible for services under P.L. 99-457. The "parent partners" (family care managers) will provide support to parents of young children with problems, serve as their advocates in helping them assume their role as primary caretakers for their children, and work closely with CSHN staff in determining the needs of the family and in assuring the family's understanding and cooperation with recommendations and with the individual family service plan.

TITLE: CHSC Parent Partnership

PRINCIPAL INVESTIGATOR: Richard P. Nelson, M.D.
University of Iowa
Department of Pediatrics
Child Health Specialty Clinics
Iowa City, IA 52242

PHONE NUMBER: (319) 356–1118

PROJECT PERIOD: 10/01/88 – 09/30/94

SUMMARY:

This project seeks to strengthen family-centered care for Iowa children with special health care needs by expanding parent participation in CHSC services department, by creating a statewide parent consultant network, and by enhancing community opportunities for parents to meet with one another and with professionals in a family-oriented experience. Program plans include an annual statewide issues forum; a regional parent consultant network composed of 2 parents from each of the 13 CHSC service regions; and family enrichment weekends designed to bring together parents and children for discussion, reflection, and recreation.

TITLE: CAPP National Resource Parent Center

PRINCIPAL INVESTIGATOR: Betsy Anderson
Federation For Children with Special Needs
312 Stuart Street, Second Floor
Boston, MA 02116

PHONE NUMBER: (617) 482-2915

PROJECT PERIOD: 07/01/89 – 06/30/94

SUMMARY:

This project is designed to help parents acquire the skills and knowledge necessary to enable them to assume a greater role in caring for their children and to participate collaboratively with health professionals in program and policy formation. The project has framed three major goals: (1) To strengthen parent leadership capabilities through a system of technical assistance; (2) to expand the Collaboration Among Parents and Health Professionals (CAPP) regional system to coordinate with parent organizations, professional groups, and State health departments; and (3) to develop effective parent-professional liaisons at all levels of health care.

TITLE: Factors Affecting the Coping of Parents of Disabled Children

PRINCIPAL INVESTIGATORS: Drs. Sylvia Walker, Charles Asbury, and Faye Belgrave
Howard University
2900 Van Ness Street, N.W.
Washington, D.C 20001

PHONE NUMBER: (202) 806–8727

PROJECT PERIOD: 07/01/88 – 06/03/90

SUMMARY:

Purpose/Objective: Families raising a disabled child experience an increased amount of stress. The purpose of this research is to identify factors that enable minority families to effectively cope with the stressors of having a child with a disability.

Methodology: One hundred parents of children with disabilities will be recruited through parent organizations and support groups in the Washington, D.C. metropolitan area. These parents will be administered an inventory containing measures of coping, adjustment and social support. Demographic information on parent and child will also be obtained.

Current Status: A draft copy of the instrument has been developed. Measures of coping, adjustment, and social support have been reviewed and tentatively selected. The next phase will involve the finalization of the study instrument, the recruitment of parents to participate in the study, and the collection of data.

TITLE: Mental Health Service Utilization by Children and Parents

PRINCIPAL INVESTIGATOR: Herbert Schlesinger, Ph.D.
Graduate Faculty
New School for Social Research
65 Fifth Avenue, Room 341
New York, NY 10003

PHONE NUMBER: (617) 956–5031

PROJECT PERIOD: 09/89 – 08/91

SUMMARY:

Few empirical research data are currently available on use of mental health services by children and adolescents enrolled in large health insurance plans. The overall goal of this research is to investigate and document patterns of utilization of mental health services by 45,000 children and adolescents and their parents in the Blue Cross/Blue Shield Federal Employee Program (FEP) during the 10-year period 1974–1983. The investigators are also examining utilization of other types of medical care, ratios of inpatient to outpatient services, and service costs. The study builds on prior NIMH-supported research (RO1MH40479) by Dr. Schlesinger and colleagues and utilizes database previously assembled from FEP claims and enrollment files and the Office of Personnel Management (OPM) files.

TITLE: Parent-Pediatric Partnership

PRINCIPAL INVESTIGATOR: Jean L. Stewart, M.A., M.P.H.
Zero-to-Three Hawaii Project
3627 Kilauea Avenue, Suite 106
Honolulu, HI 97816

PHONE NUMBER: (808) 735–0434

PROJECT PERIOD: 10/01/89 – 09/30/94

SUMMARY:

This project aims to develop a model for providing comprehensive, coordinated, family-centered, multidisciplinary care for environmentally at-risk infants and toddlers in low-income, culturally diverse settings. Each participating family will be assigned to a medical home with a pediatrician. The families then will be tracked through one of two demonstration sites (one urban and the other rural). A care coordinator will be assigned to each site and will be responsible for facilitating development of an individualized medical and educational support plan for each family.

TITLE: Parent to Parent National Survey Project

PRINCIPAL INVESTIGATOR: Betsy Santelli, M.S.
Beach Center on Families and Disability
3111 Haworth
The University of Kansas
Lawrence, KS 66045

PHONE NUMBER: (913) 864–7600

PROJECT PERIOD: 07/01/90 – 06/30/91

SUMMARY:

While the Parent to Parent model of matching an experienced or "veteran" parent of a family member with a disability in a one-to-one relationship with a new or "referred" parent as a way of providing emotional and informational support to families meeting the challenges of a disability has been available to families for 20 years, there has been very little research aimed at describing just what it is that Parent to Parent programs do for and with families that seems to make them so helpful. Moreover, most Parent to Parent programs are informal, organized and operated by volunteer parents, and thus often lack the visibility to both families and professionals that is so important for connecting families with the Parent to Parent experience, and for lending credibility to the Parent to Parent approach. This project has:

- Compiled a list of 650 Parent to Parent programs nationwide;
- Completed the survey of Parent to Parent program administrators;
- Presented the preliminary results of the survey of administrators at a number of conferences;
- Prepared an information packet on the Parent to parent model for families and professionals;
- Responded to requests for information from families;
- Assumed informally the role of Parent to Parent clearinghouse.

This project will:

- Conduct a national survey of 3,000 referred parents and 1,600 veteran parents to learn about the experiences of parents in Parent to Parent;
- Compile and analyze all of the survey data and use the data to develop the following products for families and professionals: 1) a comprehensive summary of the survey results, 2) a national resource directory of Parent to Parent programs, 3) a manual on best practices in Parent to Parent Program development, 4) training materials to accompany the manual on best practices, 5) an annotated bibliography of the literature and of Parent to Parent program-developed materials.
- Disseminate products of the project and continue to serve as a resource to families and professionals.

TITLE:	Psychosocial Determinants of Children's Primary Care Use
PRINCIPAL INVESTIGATOR:	Anne W. Riley, R.N., Ph.D. Johns Hopkins University Kennedy Institute 707 North Broadway, Room 205 Baltimore, MD 21205
PHONE NUMBER:	(301) 522–9455
PROJECT PERIOD:	08/88 – 06/91

SUMMARY:

To identify the mental health determinants of pediatric medical care utilization, Dr. Riley is conducting a two-year, prospective study of children (ages 5–13) and their parents recruited from low, medium, and high users of medical care services in a large, suburban health maintenance organization. Baseline retrospective data are being collected on medical care utilization and morbidity. Prospective data are being collected on: children's health and behavioral status, parents' mental health status and learned ways of responding to symptoms and distress, stressful life events, and family functioning. The study results are expected to provide the biopsychosocial theoretical structure required to determine the role of modifiable psychosocial factors in appropriate and inappropriate pediatric care seeking.

TITLE: Statewide Parent Organization Demonstration

PRINCIPAL INVESTIGATOR: Nancy Koroloff, Ph.D.
Research and Training Center on Family Support and Children's Mental Health
Regional Research Institute for Human Services
Portland State University
P.O. Box 751
Portland, OR 97207–0751

PHONE NUMBER: (503) 725–4040

PROJECT PERIOD: 10/01/89 – 09/30/94

SUMMARY:

The Statewide Parent Organization Demonstration Project provides support for the development of statewide parent organization for families of children with emotional disorders. In 1988, the Portland Research and Training Center funded five 12-month demonstration projects to develop model statewide parent organizations in Hawaii, Minnesota, Montana, Virginia and Wisconsin. Building upon the continued success of these organizations since their original funding, three additional one-year projects were added in New Jersey, Indiana and Kentucky.

The Statewide Parent Organization Project has two major goals: (1) to stimulate and support the development of model statewide entities that have the capacity to provide technical assistance to parents and parent organizations within states; and (2) to evaluate the conceptualization and implementation, and outcome of these projects. The purpose of the evaluation is to examine the issues that arise during the process of establishing a statewide parent organization and to track the impact of their activities. Understanding what does and does not work will help policy-makers better anticipate the supports needed by parent organizations in other states as they extend services to a wider geographic area and a greater variety of parents.

TITLE: Training Milieu Language Trainers

PRINCIPAL INVESTIGATOR:

Ann P. Kaiser
Department of Special Education
Peabody College/Vanderbilt University
Nashville, TN 37202

PHONE NUMBER: (615) 322–8186

PROJECT PERIOD: 10/01/87 – 09/31/90

SUMMARY:

This project investigated the training of parent trainers to teach parents to use milieu language teaching with their preschool children with handicaps. Milieu language teaching is a naturalistic intervention that teaches functional language skills in everyday interactional contexts. The purpose of the project was threefold: (a) to replicate and extend systematically previous research demonstrating that milieu teaching by parents can be effective in improving children's functional communication skills; (b) to determine the specific skills needed by parent trainers to insure rapid acquisition of the milieu teaching procedures by parents; (c) to compare trainer acquisition of critical training skills in a variety of trainer training formats.

Family Centered, Community-Based, Comprehensive Services

TITLE: ACMS/Community-Based Care Coordination Project for CCS Children and Their Families in Los Angeles County

PRINCIPAL INVESTIGATOR: Dale C. Garell, M.D.
California Children Services of Los Angeles County
2064 Marengo Street
Los Angeles, CA 90033

PHONE NUMBER: (213) 226–2405

PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

The goals of this project are to: (1) Develop and implement an automated case management system in Los Angeles County to improve and enhance the existing California Children's Services (CCS) system; (2) establish a CCS community-based care coordinator program within Los Angeles County to coordinate and implement an individual service plan for children with special needs and their families; and (3) test the feasibility and desirability of these goals in Los Angeles County, California, and other states.

TITLE: Alabama's Care Management Project

PRINCIPAL INVESTIGATORS: Glenna Graverson, Chris Beaird
Alabama State Department of Education
Division of Rehabilitation and Crippled Children's Services
2129 East South Boulevard
Montgomery, AL 36111

PHONE NUMBER: (205) 792–0022

PROJECT PERIOD: 10/01/88 – 09/30/91

SUMMARY:

This project trains parents of older handicapped children to facilitate case management services to parents of special needs children by serving as "partners" to those parents and children eligible for services under P.L. 99-457. The "parent partners" (family care managers) will provide support to parents of young children with problems, serve as their advocates in helping them assume their role as primary caretakers for their children, and work closely with CSHN staff in determining the needs of the family and in assuring the family's understanding and cooperation with recommendations and with the individual family service plan.

TITLE: Automated Information and Data System for Improving Case Management Services for Children with Special Health Care Needs

PRINCIPAL INVESTIGATOR: Raymond M. Peterson, M.D.
San Diego–Imperial Counties
Developmental Services, Inc.
4355 Ruffin Road, Suite 206
San Diego, CA 92123–1648

PHONE NUMBER: (619) 576–2932

PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

This project aims to improve case management services by: (1) Developing a computerized system for using the Individual Program Plan/Individual Family Service Plan for intake and periodic assessments; (2) developing and disseminating a computerized directory of resources for children with special health needs; (3) expanding the network of community agencies serving these children; and (4) planning for interagency collaboration to obtain information regarding the costs and effectiveness of services for children with special health care needs. The automated system will serve to assure the integration of client evaluation with treatment planning and to coordinate services to effectively serve children with special health care needs and their families.

TITLE: Benefits of an Interdisciplinary Approach to Feeding Aversion: A Feeding Needs Project

PRINCIPAL INVESTIGATOR: C.D. Schoenwetter, M.D.
University of Wisconsin at Madison
750 University Avenue
Madison, WI 53706

PHONE NUMBER: (608) 263–6477

PROJECT PERIOD: 07/01/87 – 06/30/90

SUMMARY:

The purpose of this project is to develop a high quality, comprehensive service delivery model for medically fragile children with special needs, their families, and health care providers. Project goals include enhancing all aspects of child development related to feeding; providing an interdisciplinary team as a resource in the home community; developing an interagency linkage system to coordinate services; and developing strategies to prevent feeding aversion in future medically fragile populations.

TITLE: CHSC Parent Partnership

PRINCIPAL INVESTIGATOR: Richard P. Nelson, M.D.
University of Iowa
Department of Pediatrics
Child Health Specialty Clinics
Iowa City, IA 52242

PHONE NUMBER: (319) 356–1118

PROJECT PERIOD: 10/01/88 – 09/30/94

SUMMARY:

This project seeks to strengthen family-centered care for Iowa children with special health care needs by expanding parent participation in CHSC services department, by creating a statewide parent consultant network, and by enhancing community opportunities for parents to meet with one another and with professionals in a family-oriented experience. Program plans include an annual statewide issues forum; a regional parent consultant network composed of 2 parents from each of the 13 CHSC service regions; and family enrichment weekends designed to bring together parents and children for discussion, reflection, and recreation.

TITLE: CAPP National Resource Parent Center

PRINCIPAL INVESTIGATOR: Betsy Anderson
Federation For Children with Special Needs
312 Stuart Street, Second Floor
Boston, MA 02116

PHONE NUMBER: (617) 482–2915

PROJECT PERIOD: 07/01/89 – 06/30/94

SUMMARY:

This project is designed to help parents acquire the skills and knowledge necessary to enable them to assume a greater role in caring for their children and to participate collaboratively with health professionals in program and policy formation. The project has framed three major goals: (1) To strengthen parent leadership capabilities through a system of technical assistance; (2) to expand the Collaboration Among Parents and Health Professionals (CAPP) regional system to coordinate with parent organizations, professional groups, and State health departments; and (3) to develop effective parent-professional liaisons at all levels of health care.

TITLE: Care Management Model for Genetic Services

PRINCIPAL INVESTIGATOR: Carmen B. Lozzio, M.D.
University of Tennessee Medical Center
Developmental and Genetics Center
1924 Alcoa Highway
Knoxville, TN 37920

PHONE NUMBER: (615) 544–9031

PROJECT PERIOD: 07/01/87 – 06/30/90

SUMMARY:

This project seeks to reduce the discontinuity and fragmentation of health care delivery for children with genetic disorders in east Tennessee, to empower the parent/guardian of a child with a genetic disorder to become an effective manager of the child's special health care needs, and to determine the applicability of the MacQueen Child Profile Reporting Form as a data collection tool for genetics programs. Strategies include an active outreach program and the provision of case management services.

TITLE: Case Management for Parents of Indian Children with Special Health Care Needs

PRINCIPAL INVESTIGATOR: Randi Suzanne Malach
Southwest Communication Resources, Inc.
P.O. Box 788
Bernalillo, NM 87004

PHONE NUMBER: (505) 867–3396

PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

This project provides a model program for American Indian families and the professionals who serve them. The program goals are to identify cultural, systemic, institutional, and policy barriers that inhibit Native American family participation in the "Western" health care/case management system; improve case management by facilitating effective communication between Native American families and the non-Native American health care professionals who serve them; and increase Native American family participation in health care policy development and planning forums in order to promote changes that improve services for Native American children and families. Activities include developing a videotape illustrating effective cross-cultural communication strategies for non-Indian health care providers and training an Indian parent advocate to help families seen at IHS special pediatric clinics.

TITLE: Case Management of PKU and Galactosemia in West Virginia

PRINCIPAL INVESTIGATOR: John C. Baker, M.D.
West Virginia University
Health Sciences Center
Department of Pediatrics/Genetics
Morgantown, WV 26506

PHONE NUMBER: (304) 293-7331

PROJECT PERIOD: 10/01/89 – 09/30/90

SUMMARY:

The goal of this project is to develop a system of case management in conjunction with an existing community outreach network of genetics clinics in order to: (1) Ensure that all newborns are appropriately screened for PKU and galactosemia; (2) improve the medical care and nutrition management for children with PKU and galactosemia; (3) improve family understanding of their child's problem and nutritional needs, and community resources that are available; (4) identify and improve community services for these patients; and (5) enhance the families' ability to access local services.

TITLE: Children and Adolescents with Special Health Care Needs: Family-Centered Nursing Graduate Specialty

PRINCIPAL INVESTIGATOR: Patricia Brandt, Ph.D.
University of Washington
Nursing Department, SC-74
Seattle, WA 98195

PHONE NUMBER: (206) 545-1291

PROJECT PERIOD: 07/01/84 – 06/30/93

SUMMARY:

This project is designed to be responsive to the health care needs of children and adolescents with handicapping conditions, the health program needs of clinical nurse specialists, and the continuing education and societal needs for graduate nursing education programs. It prepares nurses at the graduate level for specialization and leadership positions in the health care of these children and adolescents.

TITLE: Clinical Epidemiology in Three Systems of Care for Youth

PRINCIPAL INVESTIGATOR:
C. Clifford Attkisson, Ph.D.
Child Services Research Group
Institute for Mental Health Services Research
703 Market Street, Suite 400
San Francisco, CA 94103

PHONE NUMBER: (415) 957–2919

PROJECT PERIOD: 09/89 – 08/94

SUMMARY:

Ventura County in California has developed a model for integration and delivery of comprehensive community-based services to children and adolescents with severe emotional disturbances. Dr. Attkisson's research is designed to complement and build upon an ongoing evaluation of the implementation of the Ventura model in three northern California counties. The study has two main thrusts. One involves collection and analysis of epidemiologic data in order to ascertain the prevalence and incidence of emotional disturbance among youth receiving services from four types of public agencies: mental health, education, social services, and juvenile justice. The other major objective is to ascertain the effectiveness of the model system of care in terms of costs and clinical outcomes.

TITLE: Community-Based Medical/Educational Program

PRINCIPAL INVESTIGATOR:
Mary Ellen Caffrey, Ph.D.
Ken-Crest Centers
One Plymouth Meeting, Room 620
Plymouth Meeting, PA 19462

PHONE NUMBER: (215) 844–4260

PROJECT PERIOD: 10/01/89 – 09/30/94

SUMMARY:

This project will add pediatric and nursing components to an existing early intervention program so that it can accommodate technology-dependent children. The center will use a coordinated approach to provide medical services, under which an individual pediatric service plan (IPSP) will be developed for each child. Target children will receive daily developmental programming which will include training in cognitive, motor, social, language, and self-help development. The project also will feature a parent training and advocacy component that aims to teach parents how to deal more effectively with their children's special medical and developmental needs.

TITLE: Coordinated Care and Case Management for Children with Special Health Needs

PRINCIPAL INVESTIGATOR: James M. Perrin, M.D.
Massachusetts General Hospital
Department of Children's Services
Fruit Street
Boston, MA 02114

PHONE NUMBER: (617) 726–1885

PROJECT PERIOD: 01/01/88 12/31/90

SUMMARY:

This project investigates the effectiveness of coordinated, community-based case management services for children through a survey of families with a range of chronic conditions in states with and without case management services. The study's hypotheses are that children and families who receive case management services (as compared to those controls who do not) will show: (1) Greater utilization of nonmedical and nonhospital services; (2) improved functional status as indicated by increased participation in age-appropriate community activities; and (3) improved psychological status.

TITLE: Coordinated Care Program for Children with Special Health Care Needs

PRINCIPAL INVESTIGATOR: Earl J. Brewer, Jr., M.D.
Kelsey-Seybold Foundation for Medical
Research and Education
700 Fannin, Suite 1860
Houston, TX 77030

PHONE NUMBER: (713) 791–8784

PROJECT PERIOD: 07/01/87 – 06/30/90

SUMMARY:

The goal of this project is to more fully meet the specialized medical, physical, and psychosocial needs of children with chronic illnesses in order to improve their functional abilities and their families' coping skills. The case management component of the project includes working with HMO health team models in Houston and at the Kaiser Permanente Southern California Medical Group as well as working with the State of Texas Coalition for Children with Unmet Health Needs and the Texas Department of Health to further develop case management centers. The project's national awareness program includes the development of plans to interest State Departments of Health and Kids on the Block groups in case management and family networking as a means of increasing awareness.

TITLE: Coordinating Mental Health Services to Children

PRINCIPAL INVESTIGATOR: Charles Glisson, Ph.D.
University of Tennessee
College of Social Work
311B Henson Hall
Knoxville, TN 37996-3333

PHONE NUMBER: (615) 974–6481

PROJECT PERIOD: 09/89 – 08/92

SUMMARY:

This research is examining the impact of an Assessment Intake and Management System (AIMS) legislated and funded by the State of Tennessee for the purpose of providing more effective coordination and integration of mental health and other services for children who have been placed in state custody. Case management teams operating within AIMS are given full responsibility and authority for making, coordinating and monitoring the results of all treatment and service decisions involving the State Departments of Mental Health, Human Services, Corrections, Education, and Health and Environment. A quasi-experimental design is being used to compare services and outcomes in the 12 counties that are participating in the AIMS pilot project with services and outcomes in two groups of six counties that are not participating in the pilot project but are similar in sociodemographic composition.

TITLE: Demonstration Project to Develop a Pediatric Service Coordination Model

PRINCIPAL INVESTIGATOR: Lyn Cooper Gill
MetroHealth Medical Center
Department of Pediatrics
3395 Scranton Road, Quad 3041
Cleveland, OH 44109

PHONE NUMBER: (216) 459–3635

PROJECT PERIOD: 10/01/88 – 09/30/91

SUMMARY:

The goal of this project is to enable families to provide home-centered care for their special needs children, when home is the best option, by establishing a service delivery system. This system will: (1) Promote the availability and accessibility of comprehensive quality services that address physical, psychosocial, spiritual, and developmental needs; (2) encourage continuity and coordination of care among all components of the child and family's interdisciplinary team; (3) promote communication among caregivers; and (4) be reimbursable, accountable, and responsive to change.

TITLE: Developing Community-Based Care/Case Management Services

PRINCIPAL INVESTIGATOR: Sam Valentine
Mississippi State Department of Health
P.O. Box 1700
Jackson, MS 39215–1700

PHONE NUMBER: (601) 960–7614

PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

This project seeks to develop a statewide system of community-based, comprehensive care/case management and family support services. Program strategies include developing a training curriculum for the skilled delivery of home-based family support services by medical professionals, paraprofessionals, and parents; piloting a respite providers' network; providing statewide training on the provision of family support services; and developing and disseminating a statewide directory of trained family support service providers.

TITLE: Diagnostic and Followup Project for Native American Children in Wisconsin with Special Health Care Needs

PRINCIPAL INVESTIGATOR: Raymond Kessel, Ph.D.
University of Wisconsin at Madison
Statewide Genetics Services Network
445 Henry Mall
Madison, WI 53706

PHONE NUMBER: (608) 263–6355

PROJECT PERIOD: 10/01/88 – 09/30/91

SUMMARY:

This project is part of an ongoing effort to identify and address issues related to developmental disabilities among Native American children in Wisconsin to assure that proper diagnostic and followup services are provided to this population. Tribes, State and local agencies, and volunteer organizations are involved in a collaborative effort to design and establish a long-term, community-based, high quality program in each tribal community in Wisconsin to serve the special health care needs of Native American children. The two main goals of the project are to: (1) Become an integral part of the tribal service systems, and (2) improve those systems in such a way that they address both the needs of developmentally disabled children and the issues related to the prevention of disabilities.

TITLE:	Families and Communities in Transition
PRINCIPAL INVESTIGATOR:	Kathy Schwaninger SKIP of New York, Inc. 500 East 83rd Street, Suite 1B New York, NY 10028
PHONE NUMBER:	(212) 734–0728
PROJECT PERIOD:	07/01/87 – 06/30/90

SUMMARY:

The purpose of this project is to encourage and expand home care as an option for families of children with special health needs. Objectives include empowering families who choose home care with the necessary skills and knowledge to become their own effective case managers; creating a collaborative system between parents and professionals in planning and caring for children; and improving and expanding both current home health and other community service provisions for children and their families.

TITLE:	Family-Centered, Community-Based Project
PRINCIPAL INVESTIGATOR:	Sandra J. Mathes Arkansas Children's Medical Services P.O. Box 1437, Slot 526 Little Rock, AR 72203
PHONE NUMBER:	(501) 682–2277
PROJECT PERIOD:	10/01/87 – 09/30/90

SUMMARY:

This project addresses the need to establish a regionalized system of community-based service centers to assist the families of children with special health care needs in coordinating and obtaining access to needed services. Strategies include instituting a multidisciplinary team to ensure coordination and service delivery through support of case planning, case management, referrals, and education of the client population and general public; and developing linkages between community service providers and the centrally located, more fully developed resources in Little Rock.

TITLE: Family-Centered, Community-Based Services for Children with Cancer

PRINCIPAL INVESTIGATOR: Beverly J. Lange, M.D.
Children's Hospital of Philadelphia
34th and Civic Center Boulevard
Philadelphia, PA 19104

PHONE NUMBER: (215) 590–2249

PROJECT PERIOD: 10/01/88 – 09/30/91

SUMMARY:

Traditionally, treatment of pediatric cancer has required high-technology, provider-intense care, which is expensive and disrupts family life and the child's socialization and education. The goal of this project is to design alternative means of treatment by: (1) Moving the delivery of some high-technology care for children with cancer from a Level III hospital to the community and home; (2) providing community-based intervention for those children at risk for learning disabilities caused by cancer or its treatment; and (3) developing a community-based system of followup services for long-term survivors.

TITLE: Family Support Project

PRINCIPAL INVESTIGATORS: Nancy Fire, R.N., M.S.
Oklahoma State Department of Health
P.O. Box 53551
Oklahoma City, OK 73152

PHONE NUMBER: (405) 271–4471

PROJECT PERIOD: 07/01/87 – 06/30/90

SUMMARY:

This project seeks to increase support to children with special health needs by addressing the lack of formal support due to fragmentary services in local communities and the lack of identification and utilization of informal support. Project objectives are to: (1) Facilitate local community groups to address formal support system services needs; (2) enable volunteer parents to visit other families in their communities, thereby enhancing informal support systems; and (3) establish a grassroots network of families and community groups across the State.

TITLE: Graduate Training in Pediatric Occupational Therapy

PRINCIPAL INVESTIGATOR: Elnora Gilfoyle, D.Sc.
Colorado State University
College of Applied Human Sciences
Gibbons Building, Room 104
Fort Collins, CO 80523

PHONE NUMBER: (303) 491-7567

PROJECT PERIOD: 10/01/87 – 06/30/92

SUMMARY:

The overall mission of this project is to develop a model curriculum that is sensitive to differing family, social, and cultural issues, interprofessional in approach, and adaptable to the needs of a variety of home and community settings. The design of the training program includes interagency collaborative relationships as an efficient means of providing effective training programs for occupational therapists and families of children with handicaps.

TITLE: Handicapped Children's Resource Center

PRINCIPAL INVESTIGATOR: Jose T. Villagomez, M.D.
Commonwealth of the Northern Mariana Islands
Department of Public Health and Environmental Services
Commonwealth Health Center
P.O. Box 409
Saipan, MP 96950

PHONE NUMBER: (670) 234-8950

PROJECT PERIOD: 07/01/87 – 06/30/90

SUMMARY:

The goal of this project is to reduce the barriers to obtaining health and educational services for children with special health care needs by providing a community-based, family-oriented system of comprehensive and coordinated services. Strategies include increasing community awareness of services; establishing interagency collaboration; and developing a centralized data collection system related to health status, service, and educational needs.

TITLE: Impact of AIDS on Dependent Infants of the Court

PRINCIPAL INVESTIGATOR: Mary Ann Lewis, M.D.
University of California, Los Angeles
School of Medicine
405 Hilgard Avenue
Los Angeles, CA 90024-1685

PHONE NUMBER: (213) 825–8476

PROJECT PERIOD: 09/89 – 08/94

SUMMARY:

This five-year study is using a pooled cross-sectional and time series design to study the impact of the AIDS epidemic on services provided to infants who are dependents of the Juvenile Court of Los Angeles. A stratified random sample of infants at high risk for AIDS, infants who are HIV positive or have AIDS, and infants whose risks are unknown are being followed prospectively for 18 months to examine health care utilization, placements and infant characteristics. The research is exploring changes that occur in placement, foster care, and adoption as the number of HIV positive and high-risk infants continues to escalate and increased pressures are placed on service systems and agencies. The research also explores effects of the AIDS epidemic on the mental health, stress and coping of caseworkers who seek to arrange placements and adoption.

TITLE: Improving Community-Based Services for Special Needs Children and Their Families in Rural Utah

PRINCIPAL INVESTIGATOR: Peter C. van Dyck, M.D., M.P.H.
Utah Department of Health
Family Health Services Division
P.O. Box 16650, 20 DFHS
Salt Lake City, UT 84116–0650

PHONE NUMBER: (801) 538–6161

PROECT PERIOD: 10/01/89 – 09/30/92

SUMMARY:

The goal of this project is to improve the functioning of special needs children and their families by providing adequate services in a rural are of the State. Outcome objectives are to: (1) Involve parents of special needs children in developing a service plan for their child; (2) improve the implementation of service plans for rural special needs children; (3) improve coordination of services to rural special needs children by local and tertiary care providers; and (4) improve the adequacy of services provided to special needs children by local and tertiary care providers.

TITLE: Improving Community-Based Systems of Care by Preparing MCH-CSHN Nurses for Their Role in Implementing P.L. 99-457

PRINCIPAL INVESTIGATOR: Gwen Lee, R.N., Ed.D.
University of Kentucky College of Nursing
760 Rose Street
Lexington, KY 40536–0232

PHONE NUMBER: (606) 233–6687

PROJECT PERIOD: 10/01/89 – 09/30/92

SUMMARY:

The goal of this project is to enhance the capability of the health care delivery system in DHHS Regions IV, V, and VI to provide community-based systems of care for infants and toddlers by preparing community-based nurses and State nurse leaders working in MCH and CSHN programs for their roles in implementing P.L. 99-457, Part H. The primary objective of this project is to enhance the competence of community-based nurses by developing a regionally focused, nationally relevant curriculum.

TITLE: LINC: Local Individualized Networks of Care

PRINCIPAL INVESTIGATOR: Barbara W. Desguin, M.D.
Michigan State University
Department of Pediatrics and Human Development
B-240 Life Sciences
East Lansing, MI 48824

PHONE NUMBER: (517) 353–2398

PROJECT PERIOD: 07/01/87 – 06/30/90

SUMMARY:

The goals of this project are to develop a comprehensive local support service network which will provide case-managed care to families with children with special health needs, and to facilitate the development of financial reimbursement plans which will assist communities in providing comprehensive, family-based support services. Four community agencies will participate in the multiprofessional network, contributing mental health, nutrition, education, health education, and social services.

TITLE: MCHIP Systems Development Project for Children with Special Health Care Needs

PRINCIPAL INVESTIGATOR:
Micki Pryer, M.D.
Federated States of Micronesia
Department of Human Resources
P.O. Box 490
Kolonia, Pohnpei, FM 96941

PHONE NUMBER: (691) 320–2619

PROJECT PERIOD: 10/01/88 – 09/30/91

SUMMARY:

The goals of this project are to: (1) Identify and analyze the handicapping conditions present in the Federated States of Micronesia; (2) introduce concepts of coordinated care services, family- and community-based networks, and case management services to the providers who care for children with special health care needs; (3) provide training for the development of communications systems and linkage networks among the agencies involved with caring for these children; and (4) consider mechanisms for the development of systems to enable the ongoing identification, monitoring, and treatment of children with special health care needs.

TITLE: MCRI Interdisciplinary Training Program

PRINCIPAL INVESTIGATOR:
Bruce Buehler, M.D.
University of Nebraska
Meyer Children's Rehabilitation Institute
444 South 44th Street
Omaha, NE 68131

PHONE NUMBER: (402) 559–5233

PROJECT PERIOD: 07/01/86 – 06/30/90

SUMMARY:

This project provides community- and center-based interdisciplinary training to graduate students in 11 disciplines. The program addresses the critical health care needs of Nebraskans while at the same time providing leadership training at the preprofessional and continuing education level. Programs and materials developed at Meyer Children's Rehabilitation Institute are disseminated nationally and regionally.

TITLE: Montana Project for Children with Special Heath Care Needs

PRINCIPAL INVESTIGATOR:
Sidney C. Pratt, M.D.
Montana Department of Health and
Environmental Sciences
Cogswell Building, Room C314
Helena, MT 59620

PHONE NUMBER: (406) 444–4740

PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

The overall goal of this project is to develop a replicable system of family-centered, community-based case management for children with special health care needs in a frontier state. Targeted communities must be under 20,000 in population and serving areas at least 50 miles from a Level II facility. The project objectives are to: (1) Upgrade case management and assessment skills of local public health nurses; (2) develop family-centered, community-based case management programs that address the needs of the family and the child with special needs; and (3) develop community-based teams that empower families to actively participate in identifying and meeting educational, social, psychological, health, and financial needs for themselves and the child with special needs.

TITLE: National and Local Models of Paraprofessional Training and Service

PRINCIPAL INVESTIGATOR:
Richard Roberts, Ph.D.
Utah State University
Early Intervention Research Institute
Logan, UT 84322-6580

PHONE NUMBER: (801) 750–3346

PROJECT PERIOD: 10/01/89 – 09/30/92

SUMMARY:

This project will develop a paraprofessional cadre of home visitors working under the supervision of public health nurses serving rural children with developmental delays. Fifty families will receive paraprofessional weekly home visiting services under this program. The program is designed to increase developmental outcomes of children and increase the social and agency support provided to rural families. A national network of home visitor programs will be established leading to sets of recommendations to the Federal Interagency Coordinating Council regarding best practices for the use of paraprofessional home visiting services.

TITLE: National Center for Family-Centered Care

PRINCIPAL INVESTIGATOR: Beverly H. Johnson
Association for the Care of Children's Health
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814

PHONE NUMBER: (301) 654–6549

PROJECT PERIOD: 07/01/89 – 06/30/94

SUMMARY:

The goals of the National Center for Family-Centered Care are to promote implementation of a family-centered approach to care for children with special health care needs; to foster parent-professional collaboration at all levels of health care; and to document the effectiveness of a family-centered approach to care for children with special health care needs.

TITLE: National Network for Children with Special Needs

PRINCIPAL INVESTIGATOR: Phyllis R. Magrab, Ph.D.
Georgetown University Child Development Center
3800 Reservoir Road, N.W.
Bles Building, Room CG-52
Washington, DC 20007

PHONE NUMBER: (202) 687–8635

PROJECT PERIOD: 07/01/89 – 06/30/94

SUMMARY:

The goal of this project is to achieve comprehensive, coordinated, community-based services for children with special health care needs and their families through collaboration among public and private agencies and parents at all levels within the service delivery system. In order to reach this goal, the program will (1) develop a national network; (2) facilitate the development of national, regional, State, and community coalitions; (3) develop resources for states and communities; (4) provide technical assistance; (5) promote collaborative interagency planning at the Federal level; and (6) improve outreach to those individuals, agencies, and institutions needed to implement family-centered, community-based, coordinated care.

TITLE: National MCH Center for Ensuring Adequate Preparation of Providers

PRINCIPAL INVESTIGATOR:
A. Joanne Gates, M.D., M.B.A.
Children's Hospital of New Orleans
200 Henry Clay Avenue
New Orleans, LA 70118

PHONE NUMBER: (504) 899–9511, ext. 386

PROJECT PERIOD: 10/01/89 – 06/30/94

SUMMARY:

The goal of this project is to establish a national center to assist States in ensuring adequate preparation of providers of care for children with complex special health needs. The center will demonstrate effective approaches to preparing care providers of these children; provide assistance to agencies and organizations in developing and coordinating systems of community-based care; and assist States in developing standards for quality assurance in care delivery to these children. Project activities will include conducting orientations in selected States, selecting and preparing a core team in each State to implement a plan to provide technical assistance and consultation, and developing a newsletter and resource library.

TITLE: National Resource Center for Community-Based Systems of Service for Children with Special Health Care Needs and Their Families

PRINCIPAL INVESTIGATORS:
Josephine Gittler, J.D.
John C. MacQueen, M.D.
University of Iowa
National Maternal and Child Health
Resource Center
Boyd Law Building
Melrose and Byington
Iowa City, IA 52242

PHONE NUMBER: (319) 335–9067

PROJECT PERIOD: 07/01/89 – 06/30/94

SUMMARY:

The goals of this project are to generate support for developing community-based service systems for children with special health care needs and their families, and to increase the capabilities of individuals and groups to engage in such systems development. To reach these goals, the project will establish an information clearinghouse initiative, an educational and training initiative, and a technical assistance initiative. These initiatives will address a broad range of needs encountered in developing community-based systems, such as interagency collaboration, case management automated information and referral systems, and linkages among health care providers.

TITLE: New England SERVE: A Planning Network for Implementing Family-Centered, Community-Based Care

PRINCIPAL INVESTIGATORS:
Susan G. Epstein, M.S.W.
Ann B. Taylor, Ed.D.
Massachusetts Health Research Institute, Inc.
101 Tremont Street, Room 615
Boston, MA 02108

PHONE NUMBER: (617) 574–9493

PROJECT PERIOD: 10/01/89 – 06/30/94

SUMMARY:

This project seeks to address three specific needs which must be met in order to facilitate successful implementation of the Surgeon General's National Agenda for Children with Special Health Needs. They are: (1) The need to build a broad base of support for family-centered, community-based care; (2) the need to implement standards of quality care in both public and private programs for children with special health needs; and (3) the need to increase access to health care financing, care coordination, and community-based services.

TITLE: Northwest REAP Project

PRINCIPAL INVESTIGATOR:
J. Albert Browder, M.D.
Oregon Health Sciences University
Child Development and Rehabilitation Center
3181 Southwest Sam Jackson Park Road
Portland, OR 97201

PHONE NUMBER: (573) 279–8093

PROJECT PERIOD: 10/01/89 – 09/30/92

SUMMARY:

The Northwest REAP (Realizing Environmental Access Potential) Project will plan, develop, and implement a family- and community-based program to provide technological equipment to Oregon and southwest Washington children and youths with disabilities. The project will focus on the provision of three interdependent components: (1) Interdisciplinary assessment teams: (2) a loan-lease program; and (3) an urban/rural outreach and followup system to assure effective utilization of the assistive devices prescribed. Family advocacy, community resource linkages, interagency agreements and service plans, and undergraduate and postgraduate professional training in the family-oriented use of technology will be project priorities.

TITLE: Nutrition Care for the Child with Special Health Care Needs

PRINCIPAL INVESTIGATOR:
Harriet H. Cloud, M.S., R.D.
University of Alabama at Birmingham
Sparks Center for Development and
Learning Disorders
P.O. Box 313
University Station
Birmingham, AL 35294

PHONE NUMBER: (205) 934-0803

PROJECT PERIOD: 09/01/88 – 06/30/93

SUMMARY:

Nutrition for the Child with Special Health Care Needs is an intensive, one-week course for multidisciplinary team members concerned the nutritional needs of this population. It is taught at two different sites, with an overall goal of improving nutrition awareness and services for the child with special health care needs.

TITLE: Outcomes of Two Intensive Service Programs for Children

PRINCIPAL INVESTIGATOR:
Mary E. Evans, Ph.D.
Director of Program Evaluation Unit
New York State Office of Mental Health
Bureau of Survey and Evaluation Research
7th Floor
44 Holland Avenue
Albany, NY 12229

PHONE NUMBER: (518) 474–2094

PROJECT PERIOD: 10/90 – 09/93

SUMMARY:

The specific aims of this project are to establish a new program model, Family-Centered Intensive Case Management (FCICM) in three rural New York State (NYS) counties, and to compare the program's outcomes with those of Family-Based Treatment (FBT), NYS's model of therapeutic foster care. FCICM provides intensive services, including parent education, respite and 24-hour crisis intervention services to natural families to keep seriously emotionally disturbed (SED) children at home, while FBT uses professional parents to provide care for SED children. The research uses a positive controlled randomized study design with multiple observations, assigning children 6–12 referred for therapeutic foster care to one of two treatment conditions. The evaluation examines provider behavior (i.e., services provided), family outcomes (e.g., adaptability and cohesion, parenting skills and self-efficacy), child outcomes (e.g., school, home and community functioning), and system outcomes (e.g., costs and system network changes).

TITLE: Parent-Pediatric Partnership

PRINCIPAL INVESTIGATOR: Jean L. Stewart, M.A., M.P.H.
Zero-to-Three Hawaii Project
3627 Kilauea Avenue, Suite 106
Honolulu, HI 97816

PHONE NUMBER: (808) 735–0434

PROJECT PERIOD: 10/01/89 – 09/30/94

SUMMARY:

This project aims to develop a model for providing comprehensive, coordinated, family-centered, multidisciplinary care for environmentally at-risk infants and toddlers in low-income, culturally diverse settings. Each participating family will be assigned to a medical home with a pediatrician. The families then will be tracked through one of two demonstration sites (one urban and the other rural). A care coordinator will be assigned to each site and will be responsible for facilitating development of an individualized medical and educational support plan for each family.

TITLE: Pediatric Pulmonary Center, New York City

PRINCIPAL INVESTIGATOR: Meyer Kattan, M.D.
Mount Sinai School of Medicine
1 Gustave L. Levy Place, Box 1202
New York, NY 10029

PHONE NUMBER: (212) 241–7788

PROJECT PERIOD: 10/01/85 – 06/30/90

SUMMARY:

The purpose of the pediatric pulmonary center is to improve community-based care for children with chronic respiratory disease by providing interdisciplinary training of professional personnel and by working together with schools and community-based health care providers. Activities to achieve these objectives include continuing education programs for health care providers, workshops for patients and parents, case management services, and research activities aimed at improving the health of children with pulmonary diseases.

TITLE: Primary Care Physicians: Caring for Low-Income Children with Special Health Needs

PRINCIPAL INVESTIGATOR: Charles P. LaVallee
Western Pennsylvania Caring Foundation, Inc.
Fifth Avenue Place, Suite 3012
Pittsburgh, PA 15222

PHONE NUMBER: (412) 255–8127

PROJECT PERIOD: 10/01/89 – 09/30/94

SUMMARY:

In this program, project staff will work with the Pennsylvania Department of Health to establish a model for a statewide program designed to provide coordinated, family-centered, community-based care for chronically ill children. The project aims to provide physicians with the resources necessary to guide the care of a chronically ill child and to give families of chronically ill children the information and support they need to interact effectively with all caregivers. Program activities will include conducting a prevalence survey to determine the parameters of the target population with respect to chronic illness and disability; performing an assessment of primary care physician in western Pennsylvania with respect to educational needs, awareness of services, and level of knowledge; and providing a continuing medical education program.

TITLE: Project CONNECT

PRINCIPAL INVESTIGATOR: Mary Beth Bruder, Ph.D.
University of Connecticut Health Center
Department of Pediatrics
Division of Child and Family Studies
270 Farmington Avenue, The Exchange
Farmington, CT 06032

PHONE NUMBER: (203) 674–1485

PROJECT PERIOD: 10/01/89 – 09/30/92

SUMMARY:

Project CONNECT will develop a model for a service delivery system of family-centered, community-based care for children with complex health needs and their families. The project will implement a demonstration model with approximately 24 families during the first year. This project will also develop and implement a training curriculum for families and service providers at both the hospital and community level. The curriculum content will include general principles of family-centered care, accessing services, case coordination/case management, funding and reimbursement, system level change/advocacy, and implementation of the standards developed by New England SERVE.

TITLE: Project Copernicus: Model for Family-Centered Case Management for Children with Special Health Care Needs

PRINCIPAL INVESTIGATOR: Judson Force, M.D.
Maryland Department of Health and Mental Hygiene
201 West Preston Street
Baltimore, MD 21201

PHONE NUMBER: (301) 225–5580

PROJECT PERIOD: 10/01/88 – 09/30/91

SUMMARY:

The concept of family-centered care has emerged from the recognition that service delivery systems need to be more responsive to the choices made by families with children with special health care needs. As the philosophy of family-centered care is embraced by parents and professionals, we face the challenge of applying these concepts to actual practice. The aim of Project Copernicus is to assist parents and professionals to develop and use family-centered care coordination activities. The project will develop, demonstrate, and evaluate training programs in family-centered care coordination, with target groups of professionals and families in urban, rural, and suburban areas of Maryland and Virginia.

TITLE: Project Linkages

PRINCIPAL INVESTIGATOR: Georgianna Larson, R.N., M.P.H.
Park Nicollet Medical Foundation
5000 West 39th Street
Minneapolis, MN 55416

PHONE NUMBER: (612) 924–2805

PROJECT PERIOD: 10/01/89 – 09/30/92

SUMMARY:

The goal of Project Linkages is to improve the quality of life and health, both physical and psychosocial, of children with asthma and their families through the development of community-based, family-centered programs effectively mobilizing local, regional, and State resources from public, private, and voluntary agencies. Project objectives are to: (1) Increase child/family/primary provider understanding of disease management through a community-based clinic team approach; (2) increase child/family/primary care provider expertise in disease management through formal and informal education; and (3) facilitate third-party payer reimbursement for health promotion, community-based services for children with asthma and epilepsy.

TITLE: Program of Family-Directed Case Management

PRINCIPAL INVESTIGATOR: Carol R. Hassler, M.D.
Vermont Department of Health
Handicapped Children's Services
1193 North Avenue
P.O. Box 70
Burlington, VT 05402

PHONE NUMBER: (802) 863–7338

PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

The goal of this project is to increase the family-centeredness of care for children with special health needs by empowering families with the knowledge and skills they need to become case managers for their children. Program strategies include: (1) Restructuring service delivery models within Handicapped Children's Services; (2) training staff in the process of family-centered case management by parents; (3) fortifying interagency coalitions; (4) developing a philosophy statement for Vermont children with special health needs that reflects a commitment to support families and community-based care; and (5) defining and implementing the case management process.

TITLE: Social Services Delivery Under Resource Constraints

PRINCIPAL INVESTIGATOR: Patrick Doreian, Ph.D.
Department of Sociology
University of Pittsburgh
2003 Forbes Quadrangle
Pittsburgh, PA 15260

PHONE NUMBER: (412) 648–7597

PROJECT PERIOD: 04/88 – 03/92

SUMMARY:

This study applies interorganizational theory to the study and understanding of contemporary systems of service for mentally ill and emotionally disturbed children and youth. The study site is three rural western Pennsylvania counties in which, as elsewhere in the United States, public services and funding streams are fragmented and dispersed among mental health, health, child welfare, educational, and juvenile justice agencies, along with auxiliary services provided by voluntary and church groups. By adopting an open systems framework for the study of organizations, and conceptualizing interorganizational ties as parts of a set of networks, the study seeks to extend knowledge of processes of adaptation and change in networks of child and youth-serving organizations affected by long-term societal trends toward continued reduction in governmental spending for services. Three annual waves of data collection are planned.

TITLE: SPRANS/MCHIP Exchange

PRINCIPAL INVESTIGATOR: William F. Henry, M.A.
Park Nicollet Medical Foundation
5000 West 39th Street
Minneapolis, MN 55416

PHONE NUMBER: (612) 927–3393

PROJECT PERIOD: 10/01/89 – 06/30/94

SUMMARY:

The purpose of this project is to provide a national resource center for SPRANS/MCHIP grantees. The SPRANS Exchange will assist States in developing and expanding family-centered, community-based systems of care through SPRANS/MCHIP project clearinghouse activities. These will include technical assistance on product development and distribution, networking and information sharing, annual national workshops, and a resource library. The SPRANS Exchange will focus on three levels of assistance to grantees, designed to decrease fragmentation and to improve the quality and accessibility of SPRANS achievements. These levels are: (1) SPRANS/MCHIP networking, (2) SPRANS product development, and (3) SPRANS/OMCH promotion.

Cultural/Geographical Focus

TITLE: Appalachian Regional Program of Juvenile Chronic Disease

PRINCIPAL INVESTIGATOR: Daniel J. Lovell, M.D., M.P.H.
Children's Hospital Medical Center
Elland and Bethesda Avenues
Pavilion 1-29
Cincinnati, OH 45229

PHONE NUMBER: (513) 559–4676

PROJECT PERIOD: 10/01/88 – 09/30/91

SUMMARY:

This project addresses the identification and management of rheumatic and other chronic childhood diseases in a poverty-stricken, rural, and predominantly Appalachian population. With the cooperation of three universities in two states, and the Kentucky Commission for Handicapped Children, the project will seek to improve the health status of children with chronic diseases by developing secondary level medical care in three rural regions of Kentucky for children with rheumatic diseases and developing secondary level medical care in three rural regions of Kentucky for children with chronic diseases. A comprehensive, community-based, family-centered program will be implemented.

TITLE: A Culturally Sensitive Assessment Model

PRINCIPAL INVESTIGATORS
James Organist, Ph.D.
Inez Tucker, Ed.D.
Native American Research and Training Center
Department of Family & Community Medicine
University of Arizona
Tucson, AZ 85719

PHONE NUMBER: (602) 621–5075

PROJECT PERIOD: 1988 – 1991

SUMMARY:

The purpose of this project is to develop a culturally sensitive vocational assessment battery for American Indians with disabilities in order to enhance the vocational rehabilitation process for this client population. Following a literature review of current assessment methods used with American Indian clients, field visitations to selected American Indian Vocational Rehabilitation (AIVR) programs, a mail survey of vocational evaluators with AIVR programs, and a national survey of current vocational assessment practices with American Indians, the principal investigators will develop and field-test a culturally sensitive vocational assessment battery. Concurrent with the field testing of the model, indigenous staff at selected AIVR settings will be trained. Evaluation data will be collected, analyzed, and as appropriate, revisions will be made in the model. The final version of the model vocational assessment battery will be available for ongoing use by trained indigenous staff following project completion. All relevant aspects of the assessment development process will be disseminated through various publications.

TITLE: Center for Rural Mental Health Care Research

PRINCIPAL INVESTIGATOR: Richard G. Smith, M.D.
University of Arkansas/Medical Science
Psychiatry & Behavioral Sciences
4301 W. Markham, Slot 554
Little Rock, AR 72205

PHONE NUMBER: (501) 686-5600

PROJECT PERIOD: 09/90 – 08/93

SUMMARY:

This Center provides an interdisciplinary environment in which to address major policy and service issues related to provision of rural mental health care. The ultimate goal of the Center is to use research as a means of improving clinical mental health care for rural populations by addressing issues of access, utilization, effectiveness, and outcome. Using the rural diversity present in the State of Arkansas as a natural laboratory, the Center is emphasizing three areas of research: (1) assessment of rural child and adolescent mental health, (2) development of a rural schizophrenia registry from information contained in Veterans Administration, Medicaid, and state mental hospital files, and (3) mental health care for rural elderly with cognitive impairment.

TITLE: Case Management for Parents of Indian Children with Special Health Care Needs

PRINCIPAL INVESTIGATOR: Randi Suzanne Malach
Southwest Communication Resources, Inc.
P.O. Box 788
Bernalillo, NM 87004

PHONE NUMBER: (505) 867-3396

PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

This project provides a model program for American Indian families and the professionals who serve them. The program goals are to identify cultural, systemic, institutional, and policy barriers that inhibit Native American family participation in the "Western" health care/case management system; improve case management by facilitating effective communication between Native American families and the non-Native American health care professionals who serve them; and increase Native American family participation in health care policy development and planning forums in order to promote changes that improve services for Native American children and families. Activities include developing a videotape illustrating effective cross-cultural communication strategies for non-Indian health care providers and training an Indian parent advocate to help families seen at IHS special pediatric clinics.

TITLE: Community-Based Genetics Services
Network for Native Americans of the
Southwest

PRINCIPAL INVESTIGATOR: H. Eugene Hoyme, M.D.
University of Arizona College of Medicine
Arizona Health Sciences Center
Section of Genetics/Dysmorphology
Department of Pediatrics
Tucson, AZ 85724

PHONE NUMBER: (602) 795–5675

PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

This project seeks to increase the utilization of genetic services by Native Americans throughout the Southwest by providing clinics and professional and community education. Project goals include developing a definition of the incidence of congenital anomalies and genetic disorders and investigating their societal impact in the target population; reducing the number of genetic disorders and congenital anomalies in the target population; and creating a heightened awareness by Native Americans and their health care providers of the role of genetics in health care and disease.

TITLE: Comprehensive Genetic Services and
Education Program for the Deaf and
Hearing Impaired

PRINCIPAL INVESTIGATOR: Kathleen E. Toomey, M.D.
St. Christopher's Hospital for Children
Section of Medical Genetics
Fifth and Lehigh Avenue
Philadelphia, PA 19133

PHONE NUMBER: (215) 427–4430 (voice) or
(215) 427–4433 (TDD)

PROJECT PERIOD: 10/01/88 – 09/30/91

SUMMARY:

This project has established goals to: (1) Provide genetic diagnostic, evaluation, and counseling services on a regular and continuing basis; (2) provide genetic counseling and educational sessions in American Sign Language (ASL) when needed; (3) establish the Center for Genetic and Acquired Deafness as a resource for professionals and lay persons regarding causes of deafness and educational interventions; (4) assess the impact of a diagnosis of deafness in a young child on the family; (5) involve a genetic counseling student and a deaf or hearing-impaired college or graduate student in the Center's projects during summer break and have them work together to develop an educational tool.

TITLE: Cross-cultural Studies of Persons with Long-term Disabilities

PRINCIPAL INVESTIGATOR:

Joyce Varney, Dr.P.H.
University of Hawaii at Manoa
John A. Burns School of Medicine
Pacific Basin Rehabilitation Research and Training Center
226 North Kuakini Street, #233
Honolulu, HI 96817

PHONE NUMBER: (808) 537–5986
(808) 531–8691 (FAX)

PROJECT PERIOD: 03/01/87 – 02/29/94

SUMMARY:

Background: Aging with a long-term disability, a relatively new but important area of study, is of special interest because of: a) the tendency toward longer life expectancy among persons with severe disabilities, and b) the increasing proportion of elderly persons in Hawaii and other Pacific Islands.

Purpose: The purpose of this research is to answer the following questions about persons with long-term disabilities (as a result of polio) who are living in two Pacific areas (Hawaii and the Marshall Islands): a) how are people coping with their long-term disabilities, b) are they experiencing new problems (including post-polio syndrome), c) how are new problems manifested, and d) what are the most appropriate treatment methods in a given cultural and geo-political context?

Methods: This is a longitudinal study to measure changes over time. Three different types of research methods are being used: a) two descriptive studies (Hawaii and the Marshall Islands) of persons who had poliomyelitis (interview, PT exam, medical exam), b) activity analyses (SORT), and c) qualitative inquiries (case studies).

The two studies were initiated in 1987. They provide unique opportunities to study aging with a disability and to learn about the impact of culture and lifestyle on those individuals.

TITLE: Demonstration of an Innovative Approach to Genetic Counseling Services for the Deaf Population

PRINCIPAL INVESTIGATOR:
Kathleen Shaver Arnos, Ph.D.
Gallaudet Research Institute
Gallaudet University
800 Florida Avenue, N.E.
Washington, DC 20002

PHONE NUMBER: (202) 651–5258

PROJECT PERIOD: 10/01/84 – 09/30/90

SUMMARY:

The purpose of this project is to overcome the barriers to genetic counseling services that are currently encountered by the deaf population. To achieve this goal, the project will: (1) Provide a comprehensive model genetics program for hearing-impaired individuals and their families at Gallaudet University; (2) integrate and coordinate the provision of genetic services to deaf clients with those provided by the District of Columbia, Commission of Public Health, Genetics Services Program; and (3) initiate extensive information dissemination and outreach education to geneticists, deafness professionals, medical professionals, and deaf consumer groups.

TITLE: Development of a Model System of Nutrition Services for Children with Disabilities

PRINCIPAL INVESTIGATOR:
New Mexico Health and Environment Department
Public Health Division
MCH Bureau and Nutrition Bureau
Runnels Building, N-3077
Santa Fe, NM 87503

PHONE NUMBER: (505) 827–2517 or 827–2350

PROJECT PERIOD: 10/01/86 – 09/30/90

SUMMARY:

This project seeks to improve the delivery of nutrition services to children of New Mexico's low-income, tricultural, rural population. Activities include a comprehensive needs assessment of existing services; education and training for health professionals, parents, and lay groups; development of nutrition education materials; development and implementation of nutrition screening, assessment, and referral procedures; assessment of funding sources; and publication of a handbook for other nutrition service projects.

TITLE: Diagnostic and Followup Project for Native American Children in Wisconsin with Special Health Care Needs

PRINCIPAL INVESTIGATOR: Raymond Kessel, Ph.D.
University of Wisconsin at Madison
Statewide Genetics Services Network
445 Henry Mall
Madison, WI 53706

PHONE NUMBER: (608) 263-6355

PROJECT PERIOD: 10/01/88 – 09/30/91

SUMMARY:

This project is part of an ongoing effort to identify and address issues related to developmental disabilities among Native American children in Wisconsin to assure that proper diagnostic and followup services are provided to this population. Tribes, State and local agencies, and volunteer organizations are involved in a collaborative effort to design and establish a long-term, community-based, high quality program in each tribal community in Wisconsin to serve the special health care needs of Native American children. The two main goals of the project are to: (1) Become an integral part of the tribal service systems, and (2) improve those systems in such a way that they address both the needs of developmentally disabled children and the issues related to the prevention of disabilities.

TITLE: Examination of the Impact of Substance Abuse on the Health and Socioeconomic Status of Disabled Non-White Person

PRINCIPAL INVESTIGATORS:
Dr. Herbert Thornhill
Mr. Denis Hosang
Howard University
2900 Van Ness Street, N.W.
Washington, DC 20001

PHONE NUMBER: (202) 806–8727

PROJECT PERIOD: 07/01/88 – 06/30/90

SUMMARY:

Purpose and Objectives: Although all segments of society are affected by the harmful effects of substance abuse, within economically disadvantaged communities, alcohol and drug abuse have had a devastating impact on the health and economic productivity of its victims. Given this assumption, it is a necessity to recognize that alcoholism and chemical dependency are major causes of disability.

The purpose of this project is to identify variables which influence substance abuse; identify strategies which may be implemented to reduce the high incidence of substance abuse, and to identify strategies and/or approaches which may be used with this target population.

Design and Methodology: Survey questionnaires will be designed to obtain data on pre-morbid conditions, medical rehabilitation facilities, and substance abuse treatment facilities. The target population will consist of all patients with the dual diagnoses of substance abuse and physical impairment served by the Department of Rehabilitation Medicine at Harlem Hospital during 1989–1991. The study will consist of 300 such patients over a three-year period. Comparative sample groups will be obtained through survey of medical rehabilitation and substance abuse treatment facilities.

Current Status of Project: At this point, data instruments have been designed and the intervention programs have gone into operation. The medical rehabilitation survey is presently being implemented and the intervention programs are functioning on schedule. The data from the project is being prepared for analysis. The next phase involves administration of the substance abuse treatment facilities survey. The intervention programs will be implemented and the data will be analyzed in an attempt to address the objectives.

TITLE: Exercise and Recreation as Rehabilitation Strategies

PRINCIPAL INVESTIGATOR:
Joyce Varney, Dr.P.H.
University of Hawaii at Manoa
John A. Burns School of Medicine
Pacific Basin Rehabilitation Research and Training Center
226 North Kaukini Street, #233
Honolulu, HI 96817

PHONE NUMBER:
(808) 537–5986;
(808) 531–8691 (FAX)

PROJECT PERIOD: 03/91 – 02/94

SUMMARY:

Background: The islands in the Pacific Basin provide a unique environment for exercise and recreation which are now recognized as important factors in: a) reducing the risk of cardiovascular disease, b) preventing obesity, and c) improving the quality of life for able-bodied persons. Few studies have researched questions about the proper type and intensity of exercise/recreation and their long-term benefits for persons with disabilities.

Purpose: Increase understanding of how exercise (in the unique context of the Pacific Basin) can impact on persons with disabilities.

Methods:

1. A cross-sectional investigation of the health status of persons using wheelchairs focusing on exercise capacity and health status: subjects were divided into two groups, those actively engaged in exercise and those who were active or sedentary.
2. Comparison of Japanese and American wheelchair marathon athletes: a survey of training and dietary habits.
3. Descriptive study (pilot) of persons served in a transitional (rehabilitation hospital to community) therapeutic recreation program: a multi-agency collaborative effort (i.e., PBRRTC, Rehabilitation Hospital of the Pacific, University of Hawaii, Physical Education and Recreation, and Honolulu Department of Parks and Recreation).
4. Investigation of the benefits of exercise: comparing persons with neuromuscular disabilities and walk/jog, swim, cycle, or do not exercise. Factors examined include: type of exercise, physiological measures, pain, and fatigue.

TITLE: Factors Affecting the Coping of Parents of Disabled Children

PRINCIPAL INVESTIGATORS: Drs. Sylvia Walker, Charles Asbury, and Faye Belgrave
Howard University
2900 Van Ness Street, N.W.
Washington, D.C 20001

PHONE NUMBER: (202) 806–8727

PROJECT PERIOD: 07/01/88 – 06/03/90

SUMMARY:

Purpose/Objective: Families raising a disabled child experience an increased amount of stress. The purpose of this research is to identify factors that enable minority families to effectively cope with the stressors of having a child with a disability.

Methodology: One hundred parents of children with disabilities will be recruited through parent organizations and support groups in the Washington, D.C. metropolitan area. These parents will be administered an inventory containing measures of coping, adjustment and social support. Demographic information on parent and child will also be obtained.

Current Status: A draft copy of the instrument has been developed. Measures of coping, adjustment, and social support have been reviewed and tentatively selected. The next phase will involve the finalization of the study instrument, the recruitment of parents to participate in the study, and the collection of data.

TITLE: Family Definitions of Health and Disability: Ethnoracial Variation

PRINCIPAL INVESTIGATOR: Joan Patterson, Ph.D.
Center for Children with Chronic Illness and Disability
Box 721 UMHC
Minneapolis, MN 55455

PHONE NUMBER: (612) 626-4032

PROJECT PERIOD: 1991 – 1993

SUMMARY:

1. How are health, disability, and illness defined by various cultural groups?
2. What are the intercorrelations between cultural definitions, family definitions, and self-perception of children with chronic illnesses and disabilities?
3. How do these definitions change across time (e.g., as the child changes developmentally and/or the exigencies of the conditions change) and what are the consequences of changing perceptions?
4. What attitudes and meanings are developed by families about their child's illness/disability and how do these shape the process of adaptation and influence child and family outcomes?
5. To what extent does family orientation (e.g., to the sick or disabled child vs. to a family who has a member with a disabling condition) predict different adaptational outcomes?

This study will focus on the identifying variation within and across racial and ethnic groups regarding: a) the subjective meanings families assign to their children's health and disability; and b) how these meanings affect their willingness to access health and education services. The sample for this cross-sectional qualitative study will consist of 15 families of children with a physical disability (e.g., spina bifida or cerebral palsy in each of three ethnoracial groups: African-America, Hispanic, non-Hispanic white. The children studies will be between the ages of birth–2 years and 8–10 years. This study, to be conducted in Year 3, will recruit participants from a sample already identified in the study of *Needs of Families of Color #9* and will build upon the findings from that study. Other participants will be recruited from the Longitudinal Study and other sources. In order to clearly describe both disability and ethnoracial issues, a comparison group of families without a disability will be recruited by asking the study families to suggest a family of their acquaintance of the same ethnoracial heritage with a similar-age child without a disability. Semi-structured, in-depth interviews will be conducted with these 90 families based, in part, on the focus group findings but will most likely emphasize those variables originally proposed: attributions regarding the causes and responsibilities for the disability; implicit and found meanings regarding health, disability, and illness; health locus of control; family schema or world view dimensions; and cognitive coping strategies. These variables, then, will be linked to the families' perceptions of need for, and utilization of, services.

TITLE:	Hawaiian Preschool Hearing Screening Follow-up
PRINCIPAL INVESTIGATOR:	Robert W. Heath, Ph.D. Kamehameha School/Bishop Estate Center for Development of Early Education Kampalama Heights Honolulu, HI 96817
PHONE NUMBER:	(808) 832-3087
PROJECT PERIOD:	05/01/89 – 04/30/91

SUMMARY:

The objective of the Native Hawaiian Hearing Project is to produce a significant improvement in the educational achievement of Hawaiian preschool children within two years.

Earlier research has established that: a) young Hawaiian children demonstrate extremely poor performance on standardized tests of language skills, b) these children are subject to a high incidence of moderate, intermittent hearing loss, and c) there is a statistically significant relationship between these two phenomena.

Our hypothesis is that a demonstrable improvement in the language competence of Hawaiian children can be achieved by the introduction of an integrated six-component communication program into preschool classrooms. To test this hypothesis, the communication program is being implemented in six Kamehameha preschool classes serving approximately 120 Hawaiian children. Five parallel Kamehameha preschool classes (approximately 100 children) are being monitored as a comparison group. The six components of the experimental program are:

1. An enhanced hearing and speech screening procedure;
2. A follow-up effort that ensures that every child who fails the screening receives appropriate medical care of speech therapy. If necessary, the project provides transportation for the parent and child to receive appropriate care;
3. The reduction of classroom ambient noise levels to an educationally-acceptable level as specified by an acoustic engineer;
4. The amplification of instructional communication to a noise level that yields an educationally effective signal-to-noise ratio;
5. The implementation of classroom teaching techniques and equipment (electronic speech trainers) designed to improve the communication competence of children experiencing moderate speech hearing difficulties;
6. An individualized home and school communication therapy program for those children who are identified as most needy in the screening.

In addition to these six interventions, the project offers a number of other services. Workshops for parents and teachers are given at school. Topics for these workshops include home language stimulation, parent-child interaction, and prevention health practices. A Hearing Project Hotline is available for parents and teachers to get quick Project help if they suspect that a child has a hearing or speech problem.

TITLE:	Improved Newborn Screening for Hemoglobinopathies
PRINCIPAL INVESTIGATOR:	Christine Papadea, Ph.D. Georgia Department of Human Resources Division of Public Health Laboratory Unit, Room 13-H 47 Trinity Avenue, S.W. Atlanta, GA 30334
PHONE NUMBER:	(404) 656–4850
PROJECT PERIOD:	10/01/89 – 09/30/90

SUMMARY:

Georgia's newborn screening program for hemoglobinopathies is presently targeted at infants of designated ethnic/racial groups considered to be at high risk for sickle cell anemia and related hemoglobinopathies. Initial data suggest that only about 80 percent of the target population is being tested and reported to the State. This retrieval failure is due, in part, to the fact that two types of neonatal blood specimens—liquid cord for hemoglobins and heel-prick on filter paper for metabolic disorders—must be collected. For various reasons, cord blood samples are not always obtained. This study will determine whether filter paper blood spots collected in the statewide newborn screening program for metabolic disorders can be used in an isoelectric focusing technique to screen for abnormal hemoglobins.

TITLE: Influence of Sex and Culture on Rehabilitation Services to American Indians with Disabilities

PRINCIPAL INVESTIGATORS:

Catherine Am Marshall, Ph.D.
Robert Schacht, Ph.D.
American Indian Rehabilitation Research and Training Center
Northern Arizona University
P.O. Box 5630
Flagstaff, AZ 86011-5630

PHONE NUMBER: (602) 523-4791

PROJECT PERIOD: 09/26/90 – 09/25/91

SUMMARY:

In a review of the literature, it is indicated that "women as a group have received differential treatment in the field of rehabilitation. They tend to have lower employment rates, make less money, and are more likely to end up in low status, low advancement jobs than disabled men" (Lesh & Marshall, 1984, p. 21). We do not have information of special needs that might exist regarding American Indian women with disabilities. The purpose of this study is to investigate the influence of both sex and culture as it affects rehabilitation service delivery to American Indians with disabilities. Data previously collected by the AIRRTC will be reanalyzed in an attempt to better understand the needs of American Indian women who have disabilities.

Research questions include:

1. Are there differences in the demographic characteristics between American Indian men and women who apply for rehabilitation services, as well as those found eligible for services?
2. Are there differences in the pattern of services provided between American Indian men and women including time spent in different statuses?
3. Are there differences in the impact and benefits between American Indian men and women at closure?
4. Are there any special service needs of American Indian women with disabilities which can be inferred from the data?

TITLE: Integrated Genetic Services for Montana Native Americans

PRINCIPAL INVESTIGATOR:
Susan O. Lewin, M.D.
Shodair Hospital
Department of Medical Genetics
P.O. Box 5539
Helena, MT 59604

PHONE NUMBER: (406) 444–7530

PROJECT PERIOD: 10/01/89 – 09/30/92

SUMMARY:

The goals of this project are to: (1) Make available local, community-based clinical genetic services to the Montana Native Americans; (2) make genetic service delivery culturally acceptable; (3) educate a broad spectrum of health care providers, community members, and students about genetics, genetic disorders, and birth defects; (4) raise the awareness of tribal leaders about the significance of genetic disease and birth defects; and (5) lessen stigmatization of Native Americans in their communities due to genetic disease and birth defects.

TITLE: MCHIP Systems Development Project for Children with Special Health Care Needs

PRINCIPAL INVESTIGATOR:
Micki Pryer, M.D.
Federated States of Micronesia
Department of Human Resources
P.O. Box 490
Kolonia, Pohnpei, FM 96941

PHONE NUMBER: (691) 320–2619

PROJECT PERIOD: 10/01/88 – 09/30/91

SUMMARY:

The goals of this project are to: (1) Identify and analyze the handicapping conditions present in the Federated States of Micronesia; (2) introduce concepts of coordinated care services, family- and community-based networks, and case management services to the providers who care for children with special health care needs; (3) provide training for the development of communications systems and linkage networks among the agencies involved with caring for these children; and (4) consider mechanisms for the development of systems to enable the ongoing identification, monitoring, and treatment of children with special health care needs.

TITLE: Minority Children in the Mental Health System

PRINCIPAL INVESTIGATOR:
David T. Takeuchi, Ph.D.
University of California
1243A Franz Hall
Los Angeles, CA 90024-1563

PHONE NUMBER: (213) 825–1775

PROJECT PERIOD: 09/90 – 08/91

SUMMARY:

Most studies of mental health services utilization by children with psychiatric disorders have neglected minority children or have used small samples of ethnic or racial minorities. Dr. Takeuchi's research is using 1983–1988 data from the Automated Information System of the Los Angeles County Department of Mental Health to examine services utilization by over 100,000 Black, Mexican, Chinese, Korean, Filipino, Japanese, and Southeast Asian children under the age of 18. The research has three specific aims: (1) examine how differences between and heterogeneity within ethnic groups are related to entry into mental health care, (2) compare treatment provided to minority and white children, and (3) analyze terminations of minority and white children from mental health care.

TITLE: Minority Cultural Initiative

PRINCIPAL INVESTIGATION: Richard Dana, Ph.D.
Research and Training Center on Family Support and Children's Mental Health
Regional Research Institute for Human Services
Portland State University
P.O. Box 751
Portland, OR 97201-0751

PHONE NUMBER: (503) 725–4040

PROJECT PERIOD: 10/01/89 – 09/30/94

SUMMARY:

The Minority Cultural Initiative Project focuses on culturally appropriate services for children and youth with serious emotional disabilities and their families. The project is using existing knowledge in the published literature and unpublished program examples as a foundation for developing models that will allow agencies to identify and deliver culturally appropriate services.

The project consists of two major phases: (1) the model development phase; and (2) the demonstration phase. In the model development phase, two parallel activities are occurring. The first entails a comprehensive review of the literature concerning culturally appropriate services and service delivery approaches for each of the four major sociocultural groups of color in the United States (i.e., African American, Asian/Pacific Islander American, Latino- or Hispanic American, and Native American peoples). The second activity in the first phase consists of identifying existing programs and practices that embody aspects of cultural competence. The second phase of the project, the demonstration phase, involves consultation and training with agencies to help them address their ability to provide culturally appropriate services to children and their families. Activities can take several forms including providing training, brokering training, identifying alternative models, recommending literature, and generally facilitating the self-help process with respect to cultural competence.

TITLE: Needs of Families of Color

PRINCIPAL INVESTIGATORS:
Robert Wm. Blum, M.D., M.P.H., Ph.D.
Paula Goldberg, PACER Center
Center for Children with Chronic Illness and Disability
Box 721 UMHC
Minneapolis, MN 55455

PHONE NUMBER: (612) 626–4032

PROJECT PERIOD: 1989 – 1994

SUMMARY:

1. What is the experience of being a Black, Hispanic, Native American, or Asian American family with a child with special health needs?
2. To what extent do ethnicity and culture contribute to the isolation or support experienced by the family?
3. What are the experiences and concerns unique to ethnic sub-populations in America?
4. What types of interventions would provide additional supports to improve the functioning of non-white children and youths with special health needs?

Families of different cultural and racial groups who have children with disabilities often experience difficulty accessing and receiving services from a primarily white, middle-class service delivery system. In this project, parent groups will be formed for African-American, Southeast Asian, Hispanic, and Native American parents of children with disabilities to provide assistance and advocacy about educational and medical concerns they experience. Annual assessments will be done of the parents': a) understanding of disabilities; b) feelings about systems that serve their children; c) self-confidence in advocating for their children; and d) attitudes about disabilities in their community. This information will be summarized in videotapes and printed materials for each cultural group and disseminated locally and nationally through Parent Training and Information Centers (PTIs).

The project director has been hired and trained. African American families with a child with a disability are being recruited and the first focus group has been held. An evaluation tool for assessing the effectiveness of the program has been developed and is being piloted on this first group of families.

TITLE: North Idaho CASSP: A Rural System of Care Model

PRINCIPAL INVESTIGATOR: Jody Lubrecht, Ph.D.
Idaho Department of Health and Welfare
Division of Family and Children's Services
450 W. State St
Towers Building
Boise, ID 83721

PHONE NUMBER: (208) 334–5700

PROJECT PERIOD: 10/90 – 09/93

SUMMARY:

Through a local demonstration model, this project will develop and evaluate a Region-wide pilot system of highly individualized and rurally-compatible alternatives to residential treatment by implementing innovative service components, including Classroom Companion and Crisis and Respite Companion Services, Treatment Family Placement Capacity, Family-Centered Hospitalization Capacity, and Wraparound Services Funding Capacity throughout the Region in order to enhance and expand upon existing Family-Centered Assessment, Family Case Management, Intensive Family Therapy and Support Services. As fewer and fewer Region I children require out-of-school and out-of-community placement, state dollars will gradually be diverted to Region I from existing residential treatment contracts for the ongoing funding of services. The target population for this demonstration will include all severely emotionally and severely behaviorally disturbed children from Region I currently out-of-school and out-of-community placement or at imminent risk for such placement (as identified via the routine provision of Departmental services to child protection, child mental health and juvenile justice services populations and via collaborative classroom projects with selected Region school districts). The implementation of a comprehensive rural system of care in Region I, and the hypothesis-based investigation of the effectiveness of such a system as compared with Region III's traditional day treatment and out-of-community residential treatment services, would allow Idaho to demonstrate to rurally-based children's services agencies nationwide, the effectiveness of individualized, para-professionally-staffed components of care to expand the range of services available to severely disturbed children and their families.

TITLE: Oklahoma Native American Genetic Services Program

PRINCIPAL INVESTIGATOR:
Edd D. Rhoades, M.D., M.P.H.
Oklahoma State Department of Health
Division of Maternal and Child Health
1000 Northeast 10th Street
P.O. Box 53551
Oklahoma City, OK 73152

PHONE NUMBER: (405) 271-6617

PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

This project seeks to develop a coordinated network of genetic services that is culturally acceptable and financially accessible to Native Americans in Oklahoma in order to increase their utilization of genetic services. Program objectives include establishing genetic clinical services at seven selected Indian Health Services hospitals and clinics; increasing identification and referral of Oklahoma Native Americans at risk for genetic disorders or birth defects; collecting and analyzing epidemiological data on the incidence and prevalence of birth defects and genetic disorders; and developing collaborative liaisons among the genetics team, Indian Health Services, and related programs.

TITLE:	Pacific Island Culture and Disability
PRINCIPAL INVESTIGATOR:	Daniel Anderson, Ed.D. University of Hawaii at Manoa John A. Burns School of Medicine Pacific Basin Rehabilitation Research and Training Center 226 North Kuakini Street, #233 Honolulu, HI 96817
PHONE NUMBER:	(808) 537–5986; (808) 531–8691 (FAX)
PROJECT PERIOD:	03/90 – 02/94

SUMMARY:

Background: There is a need to know more about how Pacific Island cultural beliefs and values influence and determine: a) perceptions of ability and disability, b) the status of individuals with disabilities, and c) the organization and delivery of rehabilitation services.

Purpose: The purpose of this activity is to explore the influence of Pacific Island culture (beliefs, values, and behaviors) on the rehabilitation process and to improve our understanding of how American-oriented concepts of rehabilitation are being transferred and transformed when practiced in the Pacific Islands.

Methods: In phase one, research has been delimited to: a) one Pacific cultural group (Samoan), b) a single disability group (persons with stroke), and c) selected cultural factors (e.g., family support) that influence perception of ability and disability, the status of persons who are disabled, and the provision of rehabilitation services. Both quantitative and qualitative research methods are used. Activities include a cyclical process of data collection and analysis to guide subsequent data collection and analysis.

TITLE: Proposal to Extend and Enhance the Utilization of Existing Genetic Services by Overcoming Ethnocultural Barriers

PRINCIPAL INVESTIGATOR:
Franklin Desposito, M.D.
University of Medicine and Dentistry of New Jersey
Medical School
Division of Human Genetics
185 South Orange Avenue
Newark, NJ 07103

PHONE NUMBER: (201) 456–4477

PROJECT PERIOD: 10/01/88 – 09/30/91

SUMMARY:

The purpose of this project is to improve the medical care of immigrant populations in Atlantic City, Camden, and Trenton, New Jersey, who face numerous barriers posed by their ethnocultural, language/communications, and financial backgrounds. A detailed system of strategies involving educational materials which are linguistically and culturally sensitive, audiovisual aids, bilingual genetic screening forms, translator selection, training, and utilization, and intercultural workshops has been developed to assist the local genetic services programs in overcoming these barriers to access.

TITLE: Psychiatric Disorders Among Native American Adolescents

PRINCIPAL INVESTIGATOR:
Harry M. Hoberman, Ph.D.
Adolescent Health Program
Harvard Street at East River Road
P.O. Box 721 UMHC
Minneapolis, MN 55455

PHONE NUMBER: (612) 625–7469

PROJECT PERIOD: 09/90 – 08/92

SUMMARY:

In this two-year research project, Dr. Hoberman will be evaluating and modifying instruments that can be used to determine the rates of independent and co-occurring psychiatric and substance abuse disorders among Native American adolescents. Questions that determine use of mental health and substance abuse services will also be tested. The instruments will be developed and modified in consultation with advisory councils in each of three tribal service area sites: the Michigan Upper Peninsula (tribes in the Bemidji Service area—primarily Chippewa), the Four Corners area (Navajo), and Mississippi (Choctaw). The developed instruments will be pilot tested on 500 adolescents. Then in consultation with the advisory councils, the instruments will be reevaluated and refined.

TITLE: San Francisco General Hospital Perinatal Genetics

PRINCIPAL INVESTIGATORS:
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William R. Crombleholme, M.D.
University of California at San Francisco
Department of OB/GYN and Reproductive Sciences
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San Francisco, CA 94143

PHONE NUMBER: (415) 821-3133

PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

The goals of this project are to (1) lower the barriers to accessing appropriate genetic counseling and testing interventions faced by the San Francisco General Hospital (SFGH) perinatal system patients, and (2) develop a model system for the delivery of genetic counseling interventions to underserved populations and disseminate the knowledge gained through the program's efforts. To achieve these goals, the program will employ genetic counselors and bilingual, bicultural counseling aides, maintain appropriate protocols for services and referrals, integrate the genetics program into the existing SFGH Perinatal System, and maintain a satellite prenatal diagnosis center at SFGH which will offer amniocentesis and maternal serum alpha-fetoprotein followup.

TITLE: Southeast Asian Birthing and Infancy Project

PRINCIPAL INVESTIGATORS:
Jennifer Cochran, M.P.H.
Jonathan Spack
Massachusetts Health Research Institute
101 Tremont Street
Boston, MA 02108

PHONE NUMBER: (617) 426-6378

PROJECT PERIOD: 10/01/89 – 09/30/92

SUMMARY:

The primary goal of the Southeast Asian Birthing and Infancy (SABAI) Project is to reduce barriers and increase access to prenatal genetic and other maternal/infant health services and information for Southeast Asian refugees in Lowell, Massachusetts. Project objectives include providing specific services to Southeast Asian women to facilitate access to care; conducting health education activities in native Southeast Asian languages; developing a strategic plan to reduce institutional barriers; facilitating appropriate referrals to genetic services; providing followup for pregnant Southeast Asian women identified with a thalassemia or other hemoglobinopathy; and improving the rate of adequate prenatal care utilization at Lowell General Hospital Prenatal Clinic.

TITLE: Southeast Asian Developmental Disabilities Project

PRINCIPAL INVESTIGATOR:
James O. Cleveland, Ed.D.
San Diego-Imperial Counties
Developmental Services, Inc.
4355 Ruffin Road, Suite 205
San Diego, CA 92123

PHONE NUMBER: (619) 576–2965

PROJECT PERIOD: 10/01/89 – 09/30/92

SUMMARY:

This project will develop a model program to reduce the ethnocultural barriers and enhance the availability and utilization of genetic and other maternal and child health services for the Southeast Asian refugee populations in San Diego County. The project will have an impact on this target population with respect to increasing the understanding, acceptance, and utilization of Western health care services. The project will enhance the understanding and sensitivity level of primary and secondary health care providers to the cultural practices, attitudes, and health care needs of this target population.

TITLE: Specialized Family ER Program with Suicide Attempters

PRINCIPAL INVESTIGATOR:
Mary J. Rotheram-Borus, Ph.D.
Research Foundation for Mental Hygiene
722 West 168 Street
New York, NY 10032

PHONE NUMBER: (212) 740–7323

PROJECT PERIOD: 09/90 – 08/95

SUMMARY:

Since family factors are of critical importance in understanding adolescent suicide attempts and are also important determinants of compliance with recommended treatment, Dr. Borus will be evaluating the effectiveness of a specialized emergency room (ER) family intervention for a consecutive series of 200 female suicide attempters aged 12–18 who are predominantly Black and Hispanic. Female suicide attempters will receive either standard ER care plus brief family therapy or a specialized ER program and brief family therapy. The specialized program will include: 90 minute crisis family intervention; a brief videotape about what families can expect therapy in therapy; training for staff in the ER, child psychiatry, and adult psychiatry on adolescent suicidality. Number of suicide reattempts and suicide-related risk factors will be assessed at 3, 6, 12, and 18 months.

TITLE: Statewide/Areawide Genetic Services

PRINCIPAL INVESTIGATOR: Cora L.E. Christian, M.D., M.P.H.
Virgin Islands Department of Health
P.O. Box 520
Christiansted
St. Croix, VI 00802

PHONE NUMBER: (809) 778–6567

PROJECT PERIOD: 05/01/86 – 04/30/90

SUMMARY:

The goal of this project is to identify, as early as possible, any genetic disorders within the Virgin Islands population. Specifically, the project will implement laboratory screening; training and education of nurses, laboratory personnel, and physicians; liaison relationships and linkages with community groups; and genetic testing and evaluation of newborns and pediatric age groups.

TITLE: The Prevalence and Distribution of Disability Among Ethnic Minorities

PRINCIPAL INVESTIGATORS: Drs. Sylvia Walker and Charles Asbury
Howard University
2900 Van Ness Street, N.W.
Washington, DC 20001

PHONE NUMBER: (202) 806–8727

PROJECT PERIOD: 07/01/88 – 06/30/90

SUMMARY:

Purpose and Objectives: Although it is estimated that specific types of disability are more prevalent among ethnic minorities than non-minority populations, there is limited readily accessible data to support this assumption. Several factors related to high minority disability rates are poor prenatal and perinatal care, nutrition and diet, an inaccessible health care system, and a lack of proper health care knowledge and education.

The purpose of this study is to determine the prevalence, incidence, and impact of disability and other related demographic variables among ethnic minorities.

Design and Methodology: The primary data source is the National Health Interview survey done by the National Center for Health Statistics (NCHS). Two data tapes (1986, 1987) covering a broad range of demographic and health related factors have been analyzed to access the most recent data pertaining to the prevalence and distribution of disability among ethnic minorities. The sample for this study consists of 62,052 persons from 23,838 households interviewed in 1986 and 1987. The target population is the resident, civilian, noninstitutionalized population residing in the United States.

Current Status of Project: Preliminary findings for chronic conditions, physical impairments, mental disorders, and nervous disorders have been discussed and highlighted in light of their prevalence, incidence, and impact among ethnic minorities. Various findings are being submitted to specific disability journals and periodicals for dissemination throughout the country. Additional data bases will be obtained from the National Center for Health Statistics for further analyses and to enable the research team to examine trends for associating focal group variables with reference variables over a specified period of time.

TITLE: Vision Screening of Deaf Students for Genetic and Support Services to Those Identified as Deaf-Blind

PRINCIPAL INVESTIGATOR: Sandra L.H. Davenport, M.D.
Minneapolis Children's Medical Center
2525 Chicago Avenue South
Minneapolis, MN 55404

PHONE NUMBER: (612) 863–5822

PROJECT PERIOD: 10/01/89 – 09/30/92

SUMMARY:

The goals of this project are to: (1) Establish a pilot project to identify potential deaf-blindness among deaf students in three types of school settings; (2) identify Type I Usher syndrome prior to vision screening from questionnaire evidence of congenital vestibular dysfunction; (3) provide genetic diagnosis and counseling to identified deaf-blind students; (4) educate families and others about the causes and functional consequences of deaf-blindness; (5) improve psychological and psychosocial support services to deaf-blind individuals and their families; and (6) participate in an interagency effort to develop effective case coordination services for deaf-blind people.

TITLE: Vocational Readiness in American Indian Learning Disabled Adolescents

PRINCIPAL INVESTIGATOR: John Dodd, Ed.D., Eastern Montana College, Billings, MT
American Indian Rehabilitation Research and Training Center
Northern Arizona University
P.O. Box 5630
Flagstaff, AZ 86011-5630

PHONE NUMBER: (602) 523–4791

PROJECT PERIOD: 09/26/90 – 09/25/91

SUMMARY:

Purpose of this project was to investigate three major issues related to educational and vocational preparation of American Indian adolescents who are learning disabled and the nature of educational and rehabilitative services available to them upon exiting from the school system.

Information has been collected from school psychologists who have a caseload which includes American Indian students. The psychologists were asked to list the evaluation instruments they use when testing American Indian children.

TITLE:	Working with Local Alliance for the Mentally Ill Organizations to Recruit Black and Hispanic Minority Families: Creation, Replication, and Field-Testing of Training and Recruitment Strategies
PRINCIPAL INVESTIGATOR:	Virginia Selleck, Ph.D. Thresholds Research Institute 561 Diversey Parkway, Suite 210A Chicago, IL 60614
PHONE NUMBER:	(312) 348–5522
PROJECT PERIOD:	09/30/90 – 09/29/95

SUMMARY:

By extending the NIMH/CSP project begun by the Alliance for the Mentally Ill of Greater Chicago (AMI-GC), Thresholds will explore strategies for the recruitment of Hispanic and Afro-American families by facilitating outreach to these communities. This training project will involve working with AMI-GC to further develop their Minority Recruitment Program to include three components: 1) developing a training manual for Alliance Executive Directors and staff/volunteers; 2) developing a photonovella or picture book for non-English speaking and/or non-reading family members; and 3) assessing the effects of outreach efforts. Effectiveness of the training will be evaluated by: 1) a phone log kept by each affiliate, recording the number and disposition of all calls made by or on behalf of minority family members; 2) comparison of proportionate representation of minorities on the board of each affiliate before and after training; and 3) focus group interviews with readers of the photonovella and with affiliate staff who have received the minority recruitment training.

Respite Care

TITLE: Development of Respite Care Materials for Families With Children Who Have Disabilities

PRINCIPAL INVESTIGATOR: Mary Lou Licwinko
CSR, Incorporated
1400 Eye Street, N.W.
Washington, DC 20005

PHONE NUMBER: (202) 842–7600

PROJECT PERIOD: 08/15/89 – 08/15/91

SUMMARY:

The purpose of this project is to produce three products designed to educate families, care providers, and the public about the need for respite care for families who have children with multiple disabilities. CSR researched, developed, and field tested two guides on respite care. The first, *Respite Care: A Guide for Parents*, is an informational guide that addresses parent's guilt, fears, and other concerns about using respite care and provides information on how to locate respite care, pay for it, et cetera. The second, *Respite Care is for Families: A Guide to Program Development*, is designed to serve as a resource for individuals and organizations interested in starting respite care programs. This guide includes information on what parents are looking for in a respite care program, the various factors to address in setting up a program, and published information on respite care programs.

The third product being produced as part of this project is a 10 minute videotape on respite care and families that use it. The tape, currently in the production stage, focuses upon real families and their experiences with respite care. The videotape is designed to introduce and explain to those unfamiliar with the concept the benefits of and the need for respite care to families with children who are disabled or who have multiple health care needs.

TITLE: Functional Analysis

PRINCIPAL INVESTIGATOR: Robert Horner, Ph.D.
Research and Training Center on
Community-Referenced Technologies for
Nonaversive Behavior Management
1761 Alder
University of Oregon
Eugene, OR 97403

PHONE NUMBER: (503) 346–5311

PROJECT PERIOD: 10/87 – 9/92

SUMMARY:

This project focuses on the procedures for conducting functional analysis of complex problem behaviors, and the process by which functional analysis information is used to build effective programs. At this time, there is broad recognition that a functional analysis is needed as part of any effective behavioral intervention. There is not consensus, however, on: a) what constitutes a functional analysis, or b) on the procedures for moving from a functional analysis to a program plan. This project will address those issues through four research studies, a curriculum module, and a review paper.

TITLE: Generalization of Intervention Gains

PRINCIPAL INVESTIGATOR: Robert Horner, Ph.D.
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PHONE NUMBER: (503) 346–5311

PROJECT PERIOD: 10/87 – 9/92

SUMMARY:

If interventions are to produce gains of lifestyle significance, they need to result in generalized effects. Both stimulus generalization and response generalization are needed. At this time, our understanding of the generalization of new responses far outstrips our understanding of generalized response suppression. This project focuses on procedures for increasing the generalization of gains from behavioral interventions targeting response reduction. The project will generate five research studies, two curriculum modules, and a review paper.

TITLE: Inservice Training

PRINCIPAL INVESTIGATOR: Robert Horner, Ph.D.
Research and Training Center on
Community-Referenced Technologies for
Nonaversive Behavior Management
1761 Alder
University of Oregon
Eugene, OR 97403

PHONE NUMBER: (503) 346–5311

PROJECT PERIOD: 10/87 – 9/92

SUMMARY:

The inservice training project focuses on inservice workshops both near RTC sites and nationally. Each project will engage in direct support to schools, work programs, residential programs, and families who request assistance with people who perform severe problem behaviors.

In addition, the RTC established a consortium of national experts who can be contacted by teachers, adult service staff and/or families to obtain local assistance. The national experts are recruited and screened by the RTC staff, and referral to the national experts occur through the RTC Clearinghouse.

The third and most ambitious of the activities under inservice training involves the delivery of intensive "expert-level" training to state training teams. The RTC is working with 15 states to establish a system of delivering local technical assistance. RTC staff deliver training to these teams over a 4–6 month period within an active "demonstration community." The demonstration community is a community program that provides support to people with severe problem behaviors. The training team receives lectures and practicum experience in the demonstration community. They then deliver training on an on-going schedule to families and providers across the state.

TITLE: Intervention Strategies for Managing Severe Excess Behavior

PRINCIPAL INVESTIGATOR: Robert Horner, Ph.D.
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1761 Alder
University of Oregon
Eugene, OR 97403

PHONE NUMBER: (503) 346–5311

PROJECT PERIOD: 10/87 – 9/92

SUMMARY:

This project will deliver 15 research studies addressing strategies for reducing severe problem behavior in typical school, work, and home settings. This research will serve as the foundation for eight curriculum modules that will translate the research results into a format and language that is readily usable by teachers and families. In addition, five review papers will be written that provide an integration of the different intervention approaches.

TITLE: Maintenance of Intervention Gains

PRINCIPAL INVESTIGATOR: Robert Horner, Ph.D.
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1761 Alder
University of Oregon
Eugene, OR 97403

PHONE NUMBER: (503) 346–5311

PROJECT PERIOD: 10/87 – 9/92

SUMMARY:

This project addresses the critical issue of maintaining intervention gains. If an intervention is to result in meaningful change for a person, the change needs to endure across time. This project focuses on those variables that affect maintenance of intervention gains. The project will generate four research studies, two curriculum modules, and two review papers.

TITLE: National Clearinghouse

PRINCIPAL INVESTIGATOR: Robert Horner, Ph.D.
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1761 Alder
University of Oregon
Eugene, OR 97403

PHONE NUMBER: (503) 346–5311

PROJECT PERIOD: 10/87 – 9/92

SUMMARY:

The RTC has established a national clearinghouse for information about nonaversive procedures. A bulletin board has been established on SpecialNet, and a 1–800 telephone number has been established for families, teachers, service providers, etc., to call. Persons who call obtain a) referrals to local experts, b) written material on behavioral support, and c) referral to other organizations that provide technical assistance.

TITLE: National Collaboration

PRINCIPAL INVESTIGATOR: Robert Horner, Ph.D.
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1761 Alder
University of Oregon
Eugene, OR 97403

PHONE NUMBER: (503) 346–5311

PROJECT PERIOD: 10/87 – 9/92

SUMMARY:

This small project within the RTC is designed to promote and encourage collaboration and integration of work on nonaversive behavioral interventions by scholars not associated with the RTC. Each year, two individuals are invited to conduct research studies that extend our knowledge of behavioral support for people with severe problem behaviors. These individuals each receive a $3,000 stipend from the RTC, and their work is incorporated into the overall theoretical and pragmatic approach developed during the course of the project.

TITLE: National Conference

PRINCIPAL INVESTIGATOR: Robert Horner, Ph.D.
Research and Training Center on
Community-Referenced Technologies for
Nonaversive Behavior Management
1761 Alder
University of Oregon
Eugene, OR 97403

PHONE NUMBER: (503) 346–5311

PROJECT PERIOD: 10/87 – 9/92

SUMMARY:

Each year, the RTC hosts a national conference for families, teachers, direct service providers, researchers, and policy personnel that provides current advances in research and practice on nonaversive technology. The conference has a minimal registration fee to promote the attendance of as many people as possible.

TITLE: Normalizing the Social Behavior of Children with Autism

PRINCIPAL INVESTIGATOR: Gail G. McGee, Ph.D.
University of Massachusetts at Amherst
Walden Learning Center
Department of Psychology
University of Massachusetts
Amherst, MA 01003

PHONE NUMBER: (413) 545–4791

PROJECT PERIOD: 10/01/88 – 09/30/91

SUMMARY:

The purpose of this project is to study the definition, assessment, and treatment of the severe social disabilities associated with autism. There are three concurrent and interactive research tracks. First, there are a series of studies of the ongoing probabilities of naturally-occurring social behaviors in a preschool setting, which contribute to the definition of the targets of social interventions, as well as to the evaluation of treatment outcomes. An inter-disciplinary team, representing divergent perspectives, is also providing input on the key differences in the social behaviors of children with autism and typical children. Finally, a series of studies is focused on interventions that address core autism deficits, and on examinations of incidental teaching process variables that promote generalized gains in social development. In sum, the goal of this project is to discover information that facilitates the long-term social integration of children with autism.

TITLE: Outcome Measures to Evaluate Behavioral Interventions

PRINCIPAL INVESTIGATOR: Robert Horner, Ph.D.
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Nonaversive Behavior Management
1761 Alder
University of Oregon
Eugene, OR 97403

PHONE NUMBER: (503) 346–5311

PROJECT PERIOD: 10/87 – 9/92

SUMMARY:

This project addresses the need to expand the range of outcome measures used to assess the effectiveness of behavioral interventions. There is a major need to examine the extent to which comprehensive interventions not only reduce problem behaviors but result in changes in how a person is living. This project will address both definitions of outcome measures and efficient strategies for indexing these outcomes in typical settings.

TITLE: Preservice Training

PRINCIPAL INVESTIGATOR: Robert Horner, Ph.D.
Research and Training Center on
Community-Referenced Technologies for
Nonaversive Behavior Management
1761 Alder
University of Oregon
Eugene, OR 97403

PHONE NUMBER: (503) 346–5311

PROJECT PERIOD: 10/87 – 9/92

SUMMARY:

Preservice training provided to prepare a) teachers, b) masters-level behavioral experts, and c) doctoral level personnel in the technology of nonaversive, community-referenced behavior management. Preservice training follows a competency-based model of instruction and adhere to the certification standards of each of the major universities participating in the RTC. During each year of the project, 35 teachers (or direct service staff), 10 local experts, and 5 doctoral students receiving training.

TITLE: Standardized Assessment of Behavioral and Emotional Problems of SED and LD Children

PRINCIPAL INVESTIGATOR: Stephanie H. McConaughy, Ph.D., PI.
University of Vermont
Department of Psychiatry
One South Prospect Street
Burlington, VT 05401

PHONE NUMBER: (802) 656–4563

PROJECT PERIOD: 09/01/88 – 08/31/91

SUMMARY:

This research is designed to compare the competencies and behavioral and emotional problems of 6- to 16-year-old children designated as Seriously Emotionally Disturbed (SED) or Learning Disabled (LD) according to criteria defined by PL 94-142 (Education of the Handicapped Act, 1977, 1981). The project utilizes two standardized rating scales developed by one of the investigators: the Child Behavior Checklist (CBCL) and Teacher Report Form (TRF). A History Form developed for the project also requests data on children's history of special education services, standardized ability and achievement test scores, and psychiatric diagnoses. Subjects will consist of children identified as SED or LD by Basic Staffing Teams according to the state regulations interpreting PL 94-142. We have obtained similar data on SED and LD children in Vermont, Pennsylvania, Florida, Michigan, Colorado, and Nebraska. The SED and LD subjects will be matched to the normative samples for the CBCL and TRF and to a sample of children referred for mental health services. All samples will be matched on sex and age.

Specific objectives of the research are: 1) to compare patterns of behavioral and emotional problems of SED and LD children obtained from standardized ratings from parents and teachers; 2) to compare the severity of problems of SED and LD children to those of normative samples of the same age and sex; 3) to compare the severity of problems of SED and LD children to those of clinically referred children of the same age and sex; 4) to identify differences in the severity and patterns of problems that discriminate SED from LD children; 5) to identify differences in competencies and school adaptive functioning that discriminate SED from LD children; 6) to identify differences in academic achievement and cognitive ability that discriminate SED from LD children; and 7) to test effects of age, sex, socioeconomic status, and state of residence on the patterns and severity of problems of SED and LD children.

TITLE: Technical Assistance

PRINCIPAL INVESTIGATOR: Robert Horner, Ph.D.
Research and Training Center on
Community-Referenced Technologies for
Nonaversive Behavior Management
1761 Alder
University of Oregon
Eugene, OR 97403

PHONE NUMBER: (503) 346–5311

PROJECT PERIOD: 10/87 – 9/92

SUMMARY:

The RTC staff provide direct technical assistance to school districts, teachers, staff, and families near each site. During the past 24 months, this technical assistance has led to the deinstitutionalization of 17 individuals and the prevention of institutionalization of another 12 students.

TITLE: Technology Utilization

PRINCIPAL INVESTIGATOR: Robert Horner, Ph.D.
Research and Training Center on
Community-Referenced Technologies for
Nonaversive Behavior Management
1761 Alder
University of Oregon
Eugene, OR 97403

PHONE NUMBER: (503) 346–5311

PROJECT PERIOD: 10/87 – 9/92

SUMMARY:

The utilization of intervention technology is a critical concern given the large gap between typical service delivery procedures and our current knowledge base. This project examines issues that affect how we can most efficiently deliver effective procedures in school, work, and home settings. The project will generate four research studies, two curriculum modules, and two review papers.

Training/Education

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TITLE: A Study of 18–22 Year Olds Who Are Completing Special Education Programs

PRINCIPAL INVESTIGATOR: Karen Unger, Ed.D.
Center for Psychiatric Rehabilitation
Boston University
730 Commonwealth Avenue
Boston, MA 02215

PHONE NUMBER: (617) 353–3549

PROJECT PERIOD: 08/01/90 – 07/31/91

SUMMARY:

The purpose of this project is to study the experiences and problems confronting young adults, aged 18–22 years, who are completing their special education programs under P.L. 94–142. This project is being conducted in collaboration with the Florida Research and Training Center for Improved Services for Seriously Emotionally Disturbed Children (FRTC), Florida Mental Health Institute, University of South Florida, Tampa, Florida. As part of its overall program of research, FRTC has been conducting a longitudinal study entitled, "The National Adolescent and Child Treatment Survey (NACTS)." Utilizing existing data from that study, new instruments were jointly developed which were administered to a representative sample of 150 subjects who were 18 years of age or older, and their parents. The new instruments were focused on the transition process, particularly to work, school and independent living, from SED programs. Questions focused on services that were helpful and those that were not. The instruments were administered by FRTC staff who went into the field in June and July to conduct personal interviews with the young adults. Parent interviews were conducted by telephone during July and August. Year two of the project will include analysis and dissemination of the findings.

TITLE: An Evaluation of Family and LEA Decisions Regarding the Appropriate Placement of Children with Technology Support

PRINCIPAL INVESTIGATOR: Pat Barber, Ph.D.
Beach Center on Families and Disability
3111 Haworth
The University of Kansas
Lawrence, KS 66045

PHONE NUMBER: (913) 864–7600

PROJECT PERIOD: 07/01/90 – 06/30/91

SUMMARY:

As an increasing number of children supported by medical technology move from the confines of health care institutions to home and community settings, school systems and families are beginning to face the challenge of providing appropriate educational services to meet the unique needs of these students. Service provision as well as the appropriate integration of many of these children into educational settings will depend on the resolution of such issues as health care costs, liability, personnel training, assessment, and the coordination of health, education, family, and related service systems. Current educational and health policies provide minimal guidance in addressing these and other factors affecting placement and the provision of services. To date, there is limited information on how service and placement decisions are made for these students. This project has:

- Completed and disseminated an Annotated Bibliography and completed and disseminated a literature review on educational services to children who are chronically ill and technology-supported;
- Contacted or interviewed by telephone over 60 parents and professionals across the country who have experience working with children who are ventilator-assisted in order to gather information about the characteristics and service needs of these children and the educational services issues related to this population;
- Conducted pilot interviews with parents of children who are ventilator-assisted, physicians, and educators as a means of confirming and supplementing information on educational service issues reported in the literature and through telephone contacts.

This project will:

- Conduct research on the factors affecting educational placement and service decisions through surveys and interviews with families of children who are ventilator-assisted and LEAs serving these children in at least six states;
- Disseminate research results through the development of a research monograph, journal articles aimed at special educators, school administrators, and school health personnel, and a handbook of "how-to" articles on practical information for families who participate in educational decisions.

TITLE: Audiology and Speech Training

PRINCIPAL INVESTIGATOR: Fred H. Bess, Ph.D.
Vanderbilt University School of Medicine
1114 19th Avenue South
Nashville, TN 37212

PHONE NUMBER: (615) 320–5353

PROJECT PERIOD: 07/01/84 – 06/30/92

SUMMARY:

This project is designed to train personnel at the master's and Ph.D. levels in speech-language pathology and audiology. The objective is to produce highly qualified professionals who are capable of serving children with communicative handicaps and their families. Special emphasis is placed on increasing the numbers of minorities within the field of communication disorders.

TITLE: Baylor Laboratory Training Program

PRINCIPAL INVESTIGATOR: Edward R.B. McCabe, M.D., Ph.D.
Baylor College of Medicine
One Baylor Plaza, T-526
Houston, TX 77030

PHONE NUMBER: (713) 798-5820

PROJECT PERIOD: 10/01/88 – 06/30/93

SUMMARY:

The Baylor Laboratory Training Program provides training in the use of molecular genetic techniques in the diagnosis of genetic disease. Trainees include graduate students, medical students, postdoctoral fellows (including two supported by this grant), scientists on sabbatical leave, and visiting scientists. An annual two-day workshop for 100 participants (physicians, genetic counselors, nurses, genetics clinic personnel, clinical laboratory personnel, and representatives of government agencies and community organizations) provides an introduction to state-of-the-art molecular genetic diagnosis. The faculty provide diagnosis and management of rare genetic disorders. The laboratories are refining and developing molecular genetic diagnostic techniques to improve their reliability, efficiency, cost effectiveness, and utility.

TITLE: Biochemical Genetics Laboratory

PRINCIPAL INVESTIGATOR: William Nyhan, M.D., Ph.D.
University of California at San Diego
Department of Pediatrics, M-009-A
LaJolla, CA 92037-0609

PHONE NUMBER: (619) 534–4150

PROJECT PERIOD: 07/01/88 – 06/03/93

SUMMARY:

This project is a demonstration laboratory devoted to the diagnosis and management of patients with inborn errors of metabolism, and serves as a referral center for patients and for samples from patients. It serves broadly in the training of health professionals in the use of state-of-the-art methods.

TITLE: Center for Developmental and Learning Disorders Training

PRINCIPAL INVESTIGATOR: Charles Alford, M.D.
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P.O. Box 313
UAB Station
Birmingham, AL 35294

PHONE NUMBER: (205) 934–0803

PROJECT PERIOD: 07/01/85 – 06/30/90

SUMMARY:

This project prepares professionals to provide health and health-related care from an interdisciplinary perspective to children with multiple handicaps and mental retardation. Training is directed toward long-term graduate and postgraduate students with career interests in maternal and child health, and is comprised of orientations, workshops, conferences, seminars, courses, and continuing education programs at both preservice and inservice levels. The center serves the five-state region of Alabama, Florida, Georgia, Mississippi, and Tennessee.

TITLE: Center for Inherited Disorders of Energy Metabolism

PRINCIPAL INVESTIGATOR: Douglas S. Kerr, M.D., Ph.D.
Case Western Reserve University
Rainbow Babies and Children's Hospital
2074 Abington Road
Cleveland, OH 44106

PHONE NUMBER: (216) 844–1286

PROJECT PERIOD: 10/01/88 –06/30/93

SUMMARY:

This center addresses the need for advanced professional training and clinical diagnostic services for evaluation and treatment of infants and children who suffer from a group of inherited diseases affecting energy production from metabolism of carbohydrate and fat. These disorders may be associated with mental retardation, muscle weakness, heart disease, and/or sudden infant death syndrome. The goals of the program are to provide advanced training for professionals with career interests in inherited metabolic disorders, to make comprehensive biochemical laboratory diagnostic services available for affected patients, to educate practitioners about recognition and treatment of these disorders, and to facilitate research to improve future diagnosis and treatment of these conditions.

TITLE: Children and Adolescents with Special Health Care Needs: Family-Centered Nursing Graduate Specialty

PRINCIPAL INVESTIGATOR: Patricia Brandt, Ph.D.
University of Washington
Nursing Department, SC-74
Seattle, WA 98195

PHONE NUMBER: (206) 545–1291

PROJECT PERIOD: 07/01/84 – 06/30/93

SUMMARY:

This project is designed to be responsive to the health care needs of children and adolescents with handicapping conditions, the health program needs of clinical nurse specialists, and the continuing education and societal needs for graduate nursing education programs. It prepares nurses at the graduate level for specialization and leadership positions in the health care of these children and adolescents.

TITLE: Comprehensive Training in Mental Retardation and Other Handicapping Conditions

PRINCIPAL INVESTIGATOR:
Clifford J. Sells, M.D.
University of Washington
Child Development and Mental Retardation Center
Clinical Training Unit, WJ-10
Seattle, WA 98195

PHONE NUMBER: (206) 545–1350

PROJECT PERIOD: 07/01/66 – 06/30/90

SUMMARY:

The Clinical Training Unit at the Child Development and Mental Retardation Center is dedicated to providing interdisciplinary training programs that ensure that specialized personnel are available to serve with children with developmental disabilities and their families. A variety of center and community-based programs provide the arena for training based on exemplary services.

TITLE: Comprehensive Training of Pediatric Dental Residents

PRINCIPAL INVESTIGATOR:
Ronald Johnson, D.D.S.
University of Southern California
School of Dentistry, Pediatric Dentistry
University Park MC 0641, Room 304A
Los Angeles, CA 90089-0641

PHONE NUMBER: (213) 743–7265

PROJECT PERIOD: 07/01/87 – 06/30/92

SUMMARY:

This training program involves a three-year structured curriculum that provides the basic scientific information, as well as an intensive clinical experience, necessary to prepare the student to deliver exemplary care for children, adolescents, and individuals who are developmentally disabled, medically compromised, or handicapped. In addition, the curriculum stresses the role of research in promoting knowledge and improving the level of dental care to the patient. A thesis based on original clinical or laboratory research is part of the requirements toward graduation from the program. A strong emphasis is placed on recognizing and meeting the dental needs of the community and on interaction with medical and nonmedical disciplines to optimize the level of care delivery for patients.

TITLE:	Counseling and Education for Families of Newborns Identified with Hemoglobinopathies
PRINCIPAL INVESTIGATOR:	Jennifer Carnes, R.N. Florida Department of Health and Rehabilitative Services Children's Medical Services 1311 Winewood Boulevard Building 5, Room 118 Tallahassee, FL 32399–0700
PHONE NUMBER:	(904) 488–1459
PROJECT PERIOD:	10/01/87 – 09/03/90

SUMMARY:

The goal of this project is to develop and implement a comprehensive education program for physicians, nurses, counselors, social workers, health educators, and other health care providers which will enable them to provide information to those identified as having sickle cell trait by the statewide newborn screening program. Community outreach and educational activities will also be conducted.

TITLE: Cross-Disciplinary Professional Training

PRINCIPAL INVESTIGATOR: Barbara J. Friesen, Ph.D.
Research and Training Center on Family Support and Children's Mental Health
Regional Research Institute for Human Services
Portland State University
P.O. Box 751
Portland, OR 97207–0751

PHONE NUMBER: (503) 725–4040

PROJECT PERIOD: 10/01/89 - 09/30/94

SUMMARY:

The Cross-Disciplinary Professional Training Project provides an opportunity to influence professional education through the development of standards of "exemplary training," and dissemination of information and program examples to faculty and students in professional schools. The project will locate, develop and test, and disseminate materials in two major areas: (1) enhancing the responsiveness of professionals and family members; and (2) promoting collaboration among professions on behalf of families whose children have serious emotional disorders.

The project has four phases. Phase I consists of three major activities: (1) conducting literature reviews of materials in the broad areas of cross-disciplinary training, parent-professional relationships, and consumer satisfaction; (2) convening a cross-disciplinary panel of experts to assist in developing criteria for identifying "model" programs; and (3) preparing a concept paper outlining principles of good cross-disciplinary education. Phase II involves identifying exemplary programs and gathering information through site visits, telephone calls and mail. Phase III includes analyzing information from Phase II and preparing written materials for dissemination, or where they do not exist, suggesting curricula and/or program approaches to be developed. Phase IV includes dissemination of information through written curriculum materials and articles and papers for presentation at major professional conferences.

TITLE: Cytogenetics Technologist Training Program

PRINCIPAL INVESTIGATOR: Shivanand R. Patil, Ph.D.
University of Iowa
Division of Medical Genetics
Department of Pediatrics
Iowa City, IA 52242

PHONE NUMBER: (319) 356–3877

PROJECT PERIOD: 10/01/88 – 06/30/93

SUMMARY:

There is an acute shortage of cyotgenetics technologists nationally and especially in the Midwest. We will develop a model program to educate and train individuals in the field of cytogenetics. We have established a full-time 9-month certificate program providing 3 months of didactic preparation and 6 months of clinical experience. We plan to expand the program in the near future from the present class size of 4 to 8 or 10 students.

TITLE: Development of a Model System of Nutrition Services for Children with Disabilities

PRINCIPAL INVESTIGATOR: New Mexico Health and Environment Department
Public Health Division
MCH Bureau and Nutrition Bureau
Runnels Building, N-3077
Santa Fe, NM 87503

PHONE NUMBER: (505) 827–2517 OR 827–2350

PROJECT PERIOD: 10/01/86 – 09/30/90

SUMMARY:

This project seeks to improve the delivery of nutrition services to children of New Mexico's low-income, tricultural, rural population. Activities include a comprehensive needs assessment of existing services; education and training for health professionals, parents, and lay groups; development of nutrition education materials; development and implementation of nutrition screening, assessment, and referral procedures; assessment of funding sources; and publication of a handbook for other nutrition service projects.

TITLE: Development of Pediatric Pulmonary Care Personnel

PRINCIPAL INVESTIGATOR: Pedro Mayol, M.D.
University of Puerto Rico
G.P.O. Box 5067
San Juan, PR 00936

PHONE NUMBER: (809) 763–4966

PROJECT PERIOD: 07/01/85 – 06/30/90

SUMMARY:

The pediatric pulmonary center operates under the philosophy of quality patient care management within an interdisciplinary framework while simultaneously training professionals in these concepts. Our goals are directed to education and training, patient and community services, and research activities.

TITLE: Development of a Prevocational Training Center

PRINCIPAL INVESTIGATOR: Patience H. White, M.D.
Children's Hospital National Medical Center
111 Michigan Avenue, N.W.
Washington, DC 20010

PHONE NUMBER: (202) 745–3203

PROJECT PERIOD: 07/01/88 – 06/30/90

SUMMARY:

The goals of this project are to determine if early vocational guidance can improve vocational readiness in adolescents with rheumatic disease and to expand the project to encompass children with chronic illnesses. The program includes prevocational assessment and counseling; an employment resource guide; outreach to children, families, and employers in the region; and a computerized data base with prevocational data.

TITLE: Educational Behavioral Program for PKU

PRINCIPAL INVESTIGATOR: Kimberlee Michals, R.D., Ph.D.
University of Illinois at Chicago
College of Allied Health Professions
840 South Wood Street
Chicago, IL 60612

PHONE NUMBER: (312) 996–8055

PROJECT PERIOD: 01/01/88 – 12/31/90

SUMMARY:

This study examines the effects of an experimental program which uses both an educational and a behavioral approach to accomplish dietary self-management by child and adolescent phenylketonuria (PKU) patients.

TITLE: English Language Acquisition in Deaf Children

PRINCIPAL INVESTIGATORS:
Peter M. Blackwell, Ph.D.
Peter DeVilliers, Ph.D.
Robert Hoffmeister, Ph.D.
The Corliss Institute in Collaboration with
Rhode Island School for the Deaf
Smith College
Clarke School for the Deaf
Boston University
292 Main Street
Warren, RI 02885

PHONE NUMBER: (401) 245–3609

PROJECT PERIOD: Year 3

SUMMARY:

The issue of language, literacy, and deafness is a major focus of concern in "Toward Equality: Education of the Deaf," the report of The Commission on the Education of the Deaf, February 1988, when it says:

> "The educational system has not been successful in assisting the majority of students who are deaf to achieve reading skills commensurate with those of their hearing peers." (page 22).

In response to that concern, the project has established as its priorities:

Priority 1. A study of the nature of English language development by deaf children based on current theories, with focus on the specific aspects of English necessary for reading and writing.

Priority 2. A study of literacy skills using measures which are theoretically motivated, and criterion-referenced.

Priority 3. Assessment of the American Sign Language competence of the subjects to study the relationships of sign language skills to the acquisition of English and literacy.

Priority 4. A study of classroom environments in which reading and writing instruction is taking place.

Priority 5. An analysis of current teacher training programs to document the relationship between teacher preparation in language and literacy and actual instructional practice.

Priority 6. Analysis of the existing literature on language acquisition and literacy development and its relevance for instruction in English for the deaf.

TITLE: Fellowship Program in Dental Care of Handicapped Children

PRINCIPAL INVESTIGATOR: Richard Corpron, D.D.S., M.S., Ph.D.
University of Michigan
School of Dentistry
1011 North University Avenue
Ann Arbor, MI 48109-1078

PHONE NUMBER: (313) 764–1523

PROJECT PERIOD: 07/01/87 – 06/30/92

SUMMARY:

This project is a training program which prepares dentists for leadership roles in administration, teaching, research, and services in dental health programs for normal and handicapped children. The program offers both an M.S. in pediatric dentistry and a dual degree program (M.S./M.P.H.) in pediatric dentistry and dental public health. The dentistry program integrates the didactic and the clinical with research training, while the dual degree program enables trainees to receive broad training in both disciplines by training individuals in a clinical discipline with experience in formulation and funding of dental health programs for normal and handicapped children. In addition, continuing education programs related to improving the dental treatment of normal and handicapped children are offered each year.

TITLE: Graduate Training in Pediatric Occupational Therapy

PRINCIPAL INVESTIGATOR: Elnora Gilfoyle, D.Sc.
Colorado State University
College of Applied Human Sciences
Gibbons Building, Room 104
Fort Collins, CO 80523

PHONE NUMBER: (303) 491–7567

PROJECT PERIOD: 10/01/87 – 06/30/92

SUMMARY:

The overall mission of this project is to develop a model curriculum that is sensitive to differing family, social, and cultural issues, interprofessional in approach, and adaptable to the needs of a variety of home and community settings. The design of the training program includes interagency collaborative relationships as an efficient means of providing effective training programs for occupational therapists and families of children with handicaps.

TITLE: Hawaiian Preschool Hearing Screening Follow-up

PRINCIPAL INVESTIGATOR: Robert W. Heath, Ph.D.
Kamehameha School/Bishop Estate
Center for Development of Early Education
Kampalama Heights
Honolulu, HI 96817

PHONE NUMBER: (808) 832-3087

PROJECT PERIOD: 05/01/89 – 04/30/91

SUMMARY:

The objective of the Native Hawaiian Hearing Project is to produce a significant improvement in the educational achievement of Hawaiian preschool children within two years.

Earlier research has established that: a) young Hawaiian children demonstrate extremely poor performance on standardized tests of language skills, b) these children are subject to a high incidence of moderate, intermittent hearing loss, and c) there is a statistically significant relationship between these two phenomena.

Our hypothesis is that a demonstrable improvement in the language competence of Hawaiian children can be achieved by the introduction of an integrated six-component communication program into preschool classrooms. To test this hypothesis, the communication program is being implemented in six Kamehameha preschool classes serving approximately 120 Hawaiian children. Five parallel Kamehameha preschool classes (approximately 100 children) are being monitored as a comparison group. The six components of the experimental program are:

1. An enhanced hearing and speech screening procedure;
2. A follow-up effort that ensures that every child who fails the screening receives appropriate medical care of speech therapy. If necessary, the project provides transportation for the parent and child to receive appropriate care;
3. The reduction of classroom ambient noise levels to an educationally-acceptable level as specified by an acoustic engineer;
4. The amplification of instructional communication to a noise level that yields an educationally effective signal-to-noise ratio;
5. The implementation of classroom teaching techniques and equipment (electronic speech trainers) designed to improve the communication competence of children experiencing moderate speech hearing difficulties;
6. An individualized home and school communication therapy program for those children who are identified as most needy in the screening.

In addition to these six interventions, the project offers a number of other services. Workshops for parents and teachers are given at school. Topics for these workshops include home language stimulation, parent-child interaction, and prevention health practices. A Hearing Project Hotline is available for parents and teachers to get quick Project help if they suspect that a child has a hearing or speech problem.

TITLE: Improving Community-Based Systems of Care by Preparing MCH-CSHN Nurses for Their Role in Implementing P.L. 99-457

PRINCIPAL INVESTIGATOR: Gwen Lee, R.N., Ed.D.
University of Kentucky College of Nursing
760 Rose Street
Lexington, KY 40536–0232

PHONE NUMBER: (606) 233–6687

PROJECT PERIOD: 10/01/89 – 09/30/92

SUMMARY:

The goal of this project is to enhance the capability of the health care delivery system in DHHS Regions IV, V, and VI to provide community-based systems of care for infants and toddlers by preparing community-based nurses and State nurse leaders working in MCH and CSHN programs for their roles in implementing P.L. 99-457, Part H. The primary objective of this project is to enhance the competence of community-based nurses by developing a regionally focused, nationally relevant curriculum.

TITLE: Interdisciplinary Education and Training of Physical Therapists

PRINCIPAL INVESTIGATOR: Kenneth J. Ottenbacher, Ph.D.
University of Wisconsin at Madison
School of Allied Health Professions
2121 Medical Sciences Center
1300 University Avenue
Madison, WI 53706

PHONE NUMBER: (608) 262–6800

PROJECT PERIOD: 10/01/87 – 06/30/92

SUMMARY:

The primary purpose of this project is to educate and train pediatric occupational and physical therapists to provide exemplary service, research, and leadership in dealing with handicapped children and their families. Five trainees per year, supported by MCH funding, receive education and training in the context of the M.S. in therapeutic science degree program at the University of Wisconsin at Madison. The graduate program is an interdisciplinary program with a strong focus on pediatric content and research/evaluation skills. Faculty and graduate students engage in collaborative research that results in publication, papers, and continuing education activities.

TITLE: Interdisciplinary Graduate Training in Developmental Disabilities

PRINCIPAL INVESTIGATOR:
Nina Scribanu, M.D.
Georgetown University
37th and O Streets, N.W.
Washington, DC 20007

PHONE NUMBER: (202) 687–8635

PROJECT PERIOD: 07/01/89 – 06/30/94

SUMMARY:

The mission of the Georgetown University Child Development Center (GUCDC), a University Affiliated Program, is to improve the quality of life for children with mental retardation, multiple handicaps, and other special health care needs and their families and to reduce the incidence of these conditions in our society. GUCDC provides interdisciplinary training of health-related professionals and prepares them for leadership in a variety of clinical, training, and consultative roles in delivering, planning, or implementing family-centered, community-based, coordinated care. Trainees participate in a core curriculum, in case management seminars, as members of GUCDC interdisciplinary teams, in community agency clinical services, and in teaching and clinical research activities.

TITLE: Interdisciplinary Training in Chronic Disabilities, UCLA

PRINCIPAL INVESTIGATOR:
James Q. Simmons III, M.D.
Neuropsychiatric Institute
760 Westwood Plaza
Los Angeles, CA 90024

PHONE NUMBER: (213) 825–0395

PROJECT PERIOD: 07/01/89 – 06/30/94

SUMMARY:

The UCLA UAP Interdisciplinary Training Program provides interdisciplinary training for 30 core leadership trainees each year at the graduate and postdoctoral level in 10 different disciplines. Its focus is on children and families with chronic disabilities, with a special emphasis on psychosocial adaptation. Leadership trainees participate in a core didactic curriculum in chronic disabilities, an interdisciplinary clinical team, their own discipline seminars, and a schedule of community observations. UAP faculty operate or coordinate seven interdisciplinary clinical services for trainees, including three on the UCLA medical campus and four in the community.

TITLE: Leadership Training for Pacific Island Nurses

PRINCIPAL INVESTIGATOR: Anne Rohweder, M.N.
University of Guam
Division of Human Ecology
UOG Station
Mangilao, GU 96923

PHONE NUMBER: (671) 734–3300, ext. 322

PROJECT PERIOD: 07/01/87 – 06/30/91

SUMMARY:

The intent of this project is to extend the education of a significant number of Pacific Island nurses beyond the associate degree or diploma in nursing by enrolling them in a second step B.S.N. program, with special provisions for maternal and child health projects to be carried out on home islands. The specific purpose of the extended education is to develop or expand leadership skills in the area of maternal and child health.

TITLE: Louisiana Pediatric Pulmonary Center

PRINCIPAL INVESTIGATOR: Robert C. Beckerman, M.D.
Tulane University School of Medicine
1430 Tulane Avenue
New Orleans, LA 70112

PHONE NUMBER: (504) 588–5601

PROJECT PERIOD: 07/01/85 – 06/30/90

SUMMARY:

The goal of the Louisiana Pediatric Pulmonary Center (LPCC) is to reduce morbidity and mortality of pediatric pulmonary disease by means of an interdisciplinary training and model care program. LPPC trains fellows in pediatric pulmonary medicine (3 years) and long-term (1 year or more) master's candidates in nursing, nutrition, and social work. Training is done by clinical supervision, didactic presentations, conferences, and research requirements. Outpatient and inpatient care is provided to infants, children, and young adults with acute and chronic pulmonary disease including cystic fibrosis, asthma, and bronchopulmonary dysplasia.

TITLE: MCRI Interdisciplinary Training Program

PRINCIPAL INVESTIGATOR: Bruce Buehler, M.D.
University of Nebraska
Meyer Children's Rehabilitation Institute
444 South 44th Street
Omaha, NE 68131

PHONE NUMBER: (402) 559–5233

PROJECT PERIOD: 07/01/86 – 06/30/90

SUMMARY:

This project provides community- and center-based interdisciplinary training to graduate students in 11 disciplines. The program addresses the critical health care needs of Nebraskans while at the same time providing leadership training at the preprofessional and continuing education level. Programs and materials developed at Meyer Children's Rehabilitation Institute are disseminated nationally and regionally.

TITLE: Medical Genetics: Diagnosis and Management

PRINCIPAL INVESTIGATOR: Charles Epstein, M.D.
University of California at San Francisco
Department of Pediatrics
Division of Medical Genetics, Box 0106
San Francisco, CA 94143

PHONE NUMBER: (415) 476–2981

PROJECT PERIOD: 07/01/84 – 06/30/93

SUMMARY:

This project provides service and training in medical genetics, with particular emphasis on comprehensive genetic counseling, the diagnosis and the management of human abnormalities of genetic origin, and the development and implementation of state-of-the-art approaches to genetic diagnosis and treatment. The project has been established because of the need to make training available in many aspects of medical genetics and to develop a system for making high quality genetic services available to a broad consumer community.

TITLE: Medical Genetics in Prevention of Mental Retardation and Birth Defects

PRINCIPAL INVESTIGATOR:
Sara C. Finey, M.D.
University of Alabama at Birmingham
UAB Station
Birmingham, AL 35294

PHONE NUMBER: (205) 934–4983

PROJECT PERIOD: 07/01/82 – 06/30/93

SUMMARY:

This project, utilizing the resources of a comprehensive medical genetics program, provides training for future leaders in the field of medical genetics. The program is based in a tertiary medical center, and graduate students and postdoctoral fellows receive didactic and laboratory instruction in cytogenetics, clinical genetics, biochemical genetics, and molecular genetics. The goals of this program include providing a cadre of leaders who possess state-of-the-art knowledge and who can implement, direct, and interpret genetic diagnostic laboratory procedures. The program will strive to reach maternal and child health populations by providing instruction in the professional schools at UAB and continuing education programs for primary care providers throughout the State.

TITLE: Mental Retardation Training

PRINCIPAL INVESTIGATOR:
Eric G. Handler, M.D., M.P.H.
Ohio State University
1341 Kinnear Road
Columbus, OH 43212-1194

PHONE NUMBER: (614) 292–5629

PROJECT PERIOD: 07/01/89 – 06/30/94

SUMMARY:

The Nisonger Center continues to provide a comprehensive and integrated program of training, service, technical assistance, research, and dissemination in the field of developmental disabilities. Central to this mission is the provision of interdisciplinary and multidisciplinary training. Professionals trained in the latest techniques of interdisciplinary service delivery continue to be one of the major problems facing service networks at local, state, regional, and national levels.

TITLE: Nursing Leadership in Pediatric Primary Chronic Care

PRINCIPAL INVESTIGATOR: Patricia Jackson
University of California at San Francisco
Department of Family Health Care Nursing
San Francisco, CA 94143-0606

PHONE NUMBER: (415) 476–4968

PROJECT PERIOD: 07/01/82 – 06/30/93

SUMMARY:

The pediatric nursing faculty of the University of California is in the process of further developing a specialty track, entitled "Clinical Nurse Specialist in Pediatric Primary Chronic Care," which will: (1) Implement a nursing curriculum focused on health maintenance, health promotion, and disease prevention in children and adolescents, with a component on handicapping conditions, chronic illnesses, and developmental disabilities; (2) prepare students with skills in case management; (3) incorporate theoretical, clinical, and leadership components from Title V and other MCH health programs; and (4) prepare students for effective participation in interdisciplinary approaches to the planning and delivery of health care services for children and families.

TITLE: OE Grant: Intensive Behavioral Treatment of Young Developmentally Delayed Children

PRINCIPAL INVESTIGATOR: Tristram Smith
University of California—Los Angeles
Department of Psychology
405 Hilgard Avenue
Los Angeles, CA 90024–1563

PHONE NUMBER: (213) 835–2319

PROJECT PERIOD: 03/15/88 – 03/15/91

SUMMARY:

The present investigation is intended to enhance the intellectual, educational and social skills of young, developmentally delayed children so that they can take better advantage of the educational opportunities provided for them in the public schools. The investigation is modeled after a recently completed and lasting study (Lovaas, 1987) showing major improvement in young autistic children. For example, 9 of 19 intensively treated children were able to enter normal classes in the public school system. The present investigation is intended to test the generality of these findings on a non-autistic population and incorporates certain methodological improvements. The program is community-based: trained student-teachers work with the children in the children's homes, assisted by the children's peers, parents, and teachers who are also taught how to provide the treatment. The children received 30 hours or more per week of 1:1 individualized treatment, lasting for 2 or more years. Intervention addresses a variety of interrelated intellectual, educational, and social behaviors, and does contain steps to help children transfer from the treatment program to the public schools.

An intensively treated experimental group (N = 20) will be compared to a control group (N = 20) comprised of children who are similar at intake. Assignment of subjects to groups is made by investigators independent of the study, using a matched-paid procedure. The control group receives a three-month parent training course from the project and then is referred to services available in the community for developmentally disabled children. A large variety of pre- and post-treatment measures are employed, administered by staff who are blind as to group assignment.

To date, we have enrolled in treatment 26 subjects, diagnosed as having mild to moderate mental retardation of unknown etiology. The mean IQ of the subjects at intake is 51 (range 36 to 75). CA at intake is 29 months (range 18 to 42 months). We plan to enroll the remaining 14 subjects needed by November 1, 1990. Preliminary assessments of outcome are consistent with our previous findings. The experimental group shows an increase of about 20 IQ points while the control group shows essentially no change. So far, six of the thirteen experimental group children are being integrated into normal classes. Thus, intensive treatment in the experimental group appears to be associated with a clinically meaningful improvement in children's intellectual, educational, and social skills.

TITLE: OHSU Interdisciplinary Training Project in MR/DD

PRINCIPAL INVESTIGATOR: Christopher P.S. Williams, M.D.
Oregon Health Sciences University
Child Development and Rehabilitation Center
P.O. Box 574
Portland, OR 97207

PHONE NUMBER: (503) 279–8317

PROJECT PERIOD: 07/01/89 – 06/30/94

SUMMARY:

The purpose of this project is to enhance the quality of life of persons who are handicapped or health impaired and their families through interdisciplinary training of professionals for leadership roles in serving this population. Its objectives include developing and implementing leadership curriculum for trainees representing 15 professional disciplines; providing an integrated network of exemplary clinical services that are family centered and responsive to the needs of such children and their families; providing training, technical assistance, and consultation to the community to strengthen community-based quality care; collaborating with major State and Federal agencies serving this population; and conducting research focused on prevention and intervention relative to the population. Training consists of guided experience in center-based clinical practicums and community programs closely interwoven with didactic activities.

TITLE: OT/PT Sc.D. Program in Therapeutic Studies

PRINCIPAL INVESTIGATOR: Anne Henderson, Ph.D.
Boston University
881 Commonwealth Avenue
Boston, MA 02215

PHONE NUMBER: (617) 353–2727 or 353–4365

PROJECT PERIOD: 07/01/87 – 06/30/92

SUMMARY:

The interdisciplinary doctoral program prepares occupational therapists and physical therapists for leadership positions in advanced practice and research with children or prepares them to teach pediatric content in entry level and advanced professional graduate programs. Current projects include development of a new specialization in chronic illness in children, a teaching tutorial, early intervention continuing education, faculty research, and database management.

TITLE: Pediatric Dentistry Training in Care of Handicapped Children

PRINCIPAL INVESTIGATOR: Jimmy Pinkham, B.S., D.D.S., M.S.
University of Iowa
College of Dentistry
Department of Pediatric Dentistry
Iowa City, IA 52242

PHONE NUMBER: (319) 335–7478

PROJECT PERIOD: 07/01/87 – 06/30/92

SUMMARY:

This project strives to ensure that participating students get exceptional training in recognizing the need for and being able to deliver specialist care that fulfills the oral health needs of chronically impaired and handicapped children (and young adults) or other children with special needs. The curriculum is designed to provide a comprehensive range of clinic, hospital, community, and research activities in an integrated multidisciplinary setting. The financial support of our trainees has allowed for recruitment of some of the best available entering pediatric dentistry graduate students from a national pool. Once on campus, these candidates are expected to grow because of faculty strength, wealth of university resources, clinical facilities, and superior multidisciplinary collaborations within the tertiary health science center here.

TITLE: Pediatric Pulmonary Center
(Gainesville, FL)

PRINCIPAL INVESTIGATOR: Arlene A. Stecenko, M.D.
University of Florida
J. Hillis Miller Health Center
Box J-296
Gainesville, FL 32610

PHONE NUMBER: (904) 392–4458

PROJECT PERIOD: 07/01/85 – 06/30/90

SUMMARY:

The purpose of this project is to provide exemplary health care for a segment of the large and increasing number of children with chronic and acute respiratory disease and to provide interdisciplinary training to alleviate the shortage of health professionals required to meet the needs of this patient population. Educational programs include interdisciplinary inpatient and outpatient management experiences, didactic curriculums, and a variety of other activities tailored to the students' interests and goals. Center faculty provide services in the form of consultative clinics and continuing education programs. Both faculty and students are active in research, patient and community education, and development of tools for patient management.

TITLE:	Pediatric Pulmonary Center (New York.City)
PRINCIPAL INVESTIGATOR:	Meyer Kattan, M.D. Mount Sinai School of Medicine 1 Gustave L. Levy Place, Box 1202 New York, NY 10029
PHONE NUMBER:	(212) 241–7788
PROJECT PERIOD:	10/01/85 – 06/30/90

SUMMARY:

The purpose of the pediatric pulmonary center is to improve community-based care for children with chronic respiratory disease by providing interdisciplinary training of professional personnel and by working together with schools and community-based health care providers. Activities to achieve these objectives include continuing education programs for health care providers, workshops for patients and parents, case management services, and research activities aimed at improving the health of children with pulmonary diseases.

TITLE:	Pediatric Pulmonary Center (Rochester, NY)
PRINCIPAL INVESTIGATOR:	John Brooks, M.D. University of Rochester 601 Elmwood Avenue Rochester, NY 14642
PHONE NUMBER:	(716) 275–2464
PROJECT PERIOD:	07/01/85 – 06/30/90

SUMMARY:

The purpose of this project is to develop new models of interdisciplinary education and to become a national model for the interdisciplinary education and regionalized care of pediatric pulmonary patients. The project is also intended to provide a comprehensive and coordinated referral service for all types of pediatric pulmonary patients. Further, project staff intend to increase the capabilities of the various communities to care for pediatric respiratory patients through expanded clinical and educational outreach to eliminate the need for long distance travel to Rochester. Additional resources are being devoted to comprehensive case management of technology-dependent infants and children with chronic respiratory disease.

TITLE: Pediatric Pulmonary Training Center (Birmingham, AL)

PRINCIPAL INVESTIGATOR:
Raymond Lyrene, M.D.
University of Alabama at Birmingham
Children's Hospital
1600 Seventh Avenue South
Birmingham, AL 35233

PHONE NUMBER: (205) 934–9845

PROJECT PERIOD: 10/01/85 – 06/30/90

SUMMARY:

This project conducts clinical training at the graduate level for nurses, social workers, and nutritionists in an active clinical setting. At the postgraduate level, pediatric pulmonary fellowships are conducted. Undergraduate courses are provided as a part of the training program for respiratory therapists. These are superimposed on a background of services rendered to patients from a wide geographic area who are afflicted with all varieties of pediatric pulmonary disease, both acute and chronic.

TITLE: Pediatric Pulmonary Training Center (Seattle, WA)

PRINCIPAL INVESTIGATOR:
Gregory J. Redding, M.D.
University of Washington
School of Medicine
Department of Pediatrics, RD-20
Seattle, WA 98195

PHONE NUMBER: (206) 543–3200

PROJECT PERIOD: 07/01/85 – 06/30/90

SUMMARY:

The purpose of the Pediatric Pulmonary Training Center at the University of Washington in Seattle is to train experts and leaders in medicine, nursing, nutrition, social work, and physical therapy who will provide and teach exemplary comprehensive care for children with pulmonary disorders, emphasizing family-centered, community-based care techniques and resource utilization. Graduates from each discipline will learn to conduct clinical and basic research on an individual and collaborative basis concerning topics involving lung biology, and prevention, diagnosis, and care of lung diseases in children. The didactic and clinical curriculums provided by core faculty in each of these disciplines within the major tertiary referral hospital for pediatric pulmonary disease in the Pacific Northwest, in conjunction with graduate classes within the professional schools of the University of Washington, provide the means to accomplish these training objectives.

TITLE: Physical Therapy in Maternal and Child Health Training

PRINCIPAL INVESTIGATOR: Pamela Catlin, Ed.D.
Emory University
1441 Clifton Road, N.E.
Atlanta, GA 30322

PHONE NUMBER: (404) 727–5564

PROJECT PERIOD: 10/01/79 – 06/30/92

SUMMARY:

The purpose of this project is to train professionally qualified physical therapists in maternal and child health care. The program emphasis is on implementation of a master of medical science program in physical therapy that stresses clinical management through prevention, early detection, and intervention in maternal and child health problems, as well as preparation of physical therapy leaders and educators with expertise in maternal and child health care.

TITLE: Project ABLE—Altering Bowel Learning Effectively

PRINCIPAL INVESTIGATOR: Michael F. Cataldo, Ph.D.
Kennedy Institute for Handicapped Children
707 North Broadway
Baltimore, MD 21205

PHONE NUMBER: (301) 522–5455

PROJECT PERIOD: 07/01/87 – 06/30/90

SUMMARY:

This project addresses the problem of fecal incontinence in children with myelomeningocele by developing an affordable instructional package for health care providers and a parent instruction program in order to help these children develop bowel control. The training program will include a videotape and written provider and parent manuals.

TITLE: Regional Biomedical Diagnostic and Treatment Program

PRINCIPAL INVESTIGATOR: Stephen Goodman, M.D.
University of Colorado Health Sciences Center
4200 East Ninth Avenue
Denver, CO 80262

PHONE NUMBER: (303) 270–7301

PROJECT PERIOD: 07/01/84 – 06/30/93

SUMMARY:

This project is the regional biochemical diagnostic and treatment program for children with inherited metabolic diseases in Colorado and the surrounding Western States. The program is now in its 18th year of providing the specialized laboratory evaluation and clinical management required for children with inborn errors of metabolism in the Rocky Mountains and High Plains Region.

TITLE: Social Work Training in Maternal and Child Health Care

PRINCIPAL INVESTIGATOR: Claire S. Rudolph, M.S.W., Ph.D.
Syracuse University
School of Social Work
Brockway Hall
Syracuse, NY 13244-6350

PHONE NUMBER: (315) 443–5550

PROJECT PERIOD: 07/01/89 – 06/30/92

SUMMARY:

The School of Social Work at Syracuse University provides a two-year, 60-credit educational program leading to the M.S.W. degree to prepare students for competent performance and leadership responsibility in the delivery of social work services in maternal and child health. The program builds on an established health care concentration with a subspecialty in maternal and child health. This project introduced education and training for competence in case management, interdisciplinary collaboration, planning and administration of maternal and child health services, and program evaluation.

TITLE: Training for the Care of the Handicapped Child

PRINCIPAL INVESTIGATOR: John D. Rau, M.D.
Indiana University
Riley Child Development Center
702 Barnhill Drive
Indianapolis, IN 46202-5225

PHONE NUMBER: (317) 274–8167

PROJECT PERIOD: 07/01/89 – 06/30/94

SUMMARY:

The Riley Child Development Center has a 20-year tradition of interdisciplinary training, diagnosis, treatment, development of case management services, support of community resources, and research to enhance services for children with chronic handicapping conditions. The fundamental elements of program planning for children with special needs and for the education/training of health and related professionals must effectively relate (1) client/family needs; (2) manpower prepared to respond to those needs; and (3) access of clients to such professionals so as to match needs and providers. The Riley Child Development Center seeks to relate these elements in a conceptual fashion useful both for individual clients and for populations of children with similar special needs, e.g., mental retardation and other long-term disabilities.

TITLE: Training for Maternal and Child Health Leadership in Care of Chronically Ill Children

PRINCIPAL INVESTIGATOR: Herbert Cohen, M.D.
Albert Einstein College of Medicine
Rose F. Kennedy Center for Mental Retardation
1410 Pelham Parkway South
Bronx, NY 10461

PHONE NUMBER: (212) 430–2440

PROJECT PERIOD: 07/01/86 – 06/30/90

SUMMARY:

The Rose F. Kennedy Center for Mental Retardation provides comprehensive interdisciplinary training for medical, dental, and nonmedical professionals in the care of children with mental retardation and developmental disabilities. Emphasis is on: (1) Long-term training of health professionals, including the training of residency physicians for assumption of leadership roles in the field; (2) the clinical training of dental specialists in the care of handicapped children; and (3) internships, fellowships, and long-term clinical experiences for nonmedical professionals. To the program's credit, the fellowship graduates have remained in the field, the majority on a full-time basis, and almost all in leadership positions.

TITLE: Training in Communication Disorders

PRINCIPAL INVESTIGATOR: Orlando L. Taylor, Ph.D.
Howard University
School of Communications
2400 Sixth Street, N.W.
Washington, DC 20059

PHONE NUMBER: (202) 636–7690

PROJECT PERIOD: 07/01/84 – 06/30/92

SUMMARY:

The purpose of this project is to provide preprofessional leadership training in communication disorders to students. This program has two major focuses, which emphasize interdisciplinary training as well as coursework, with an emphasis on issues of cultural and linguistic diversity and communication disorders. Students design an individualized program of study consisting of departmental core courses; departmental seminars in either neurological communication disorders, child language, or linguistics; and two related electives in such areas as medicine, dentistry, health care administration, and psychology. In addition, students receiving fellowships are assigned to 15 hours per week of apprenticeship activities.

TITLE: Training in Mental Retardation

PRINCIPAL INVESTIGATOR: Philip Reilly, M.D., J.D.
Eunice K. Shriver Center
200 Trapello Road
Waltham, MA 02254

PHONE NUMBER: (617) 642–0230

PROJECT PERIOD: 07/01/89 – 06/30/94

SUMMARY:

Since its inception in 1970, the Shriver Center has provided training to 750 graduate students. In fiscal year 1987, 125 events provided training to 6,000 professionals. Approximately 5,600 clients with mental retardation and other handicaps receive evaluation and program planning at the UAF each year. The UAF established one of the first early intervention programs in the region. It also offered the first demonstration project inservices to siblings of clients with mental retardation, and began the first area program for mentally retarded mothers. Presently, the UAF is the leader in New England, and a national and international leader in the prevention, early detection, and treatment of fetal alcohol syndrome.

TITLE: Training Milieu Language Trainers

PRINCIPAL INVESTIGATOR: Ann P. Kaiser
Department of Special Education
Peabody College/Vanderbilt University
Nashville, TN 37202

PHONE NUMBER: (615) 322–8186

PROJECT PERIOD: 10/01/87 – 09/31/90

SUMMARY:

This project investigated the training of parent trainers to teach parents to use milieu language teaching with their preschool children with handicaps. Milieu language teaching is a naturalistic intervention that teaches functional language skills in everyday interactional contexts. The purpose of the project was threefold: (a) to replicate and extend systematically previous research demonstrating that milieu teaching by parents can be effective in improving children's functional communication skills; (b) to determine the specific skills needed by parent trainers to insure rapid acquisition of the milieu teaching procedures by parents; (c) to compare trainer acquisition of critical training skills in a variety of trainer training formats.

TITLE: Training of Speech-Language Pathologists

PRINCIPAL INVESTIGATOR: Anthony Salvatore, Ph.D.
Our Lady of the Lake University at
San Antonio
411 Southwest 24th Street
San Antonio, TX 78285

PHONE NUMBER: (512) 434–6711, ext. 415

PROJECT PERIOD: 07/01/87 – 06/30/91

SUMMARY:

This project provides financial assistance to qualified persons interested in working with children, their mothers, and other family members with communication disorders. The ultimate objectives are to increase the number of qualified speech and language pathologists, and to increase the number of persons qualified to identify and habilitate communication disorders in minority populations.

TITLE: Training Program in Communication Disorders

PRINCIPAL INVESTIGATOR: Glenda J. Ochsner, Ph.D.
University of Oklahoma Health Sciences Center
Department of Communication Disorders
P.O. Box 26901
Oklahoma City, OK 73190

PHONE NUMBER: (405) 271–4214

PROJECT PERIOD: 07/01/66 – 06/30/92

SUMMARY:

By means of interdepartmental planning and implementation through the Departments of Otorhinolaryngology, Pediatrics, and Communication Disorders, the overall objective of the project is to provide training and experience in interdisciplinary settings to develop those competencies, skills, and attitudes required for effective performance in the team approach to evaluation and management of the child with communication disorders. Training is provided to graduate students in audiology and speech pathology; resident physicians in pediatrics, otorhinolaryngology, and neurology; medical students; and social work interns.

TITLE: Transgenerational Project for Children with Learning Disabilities, Their Parents, and Schools

PRINCIPAL INVESTIGATOR: Merceline Dahl-Regis, M.D.
Howard University Child Development Center
525 Bryant Street, N.W.
Washington, DC 20059

PHONE NUMBER: (202) 636–6973

PROJECT PERIOD: 07/01/86 – 06/30/90

SUMMARY:

This project aims to improve the academic functioning of low-income, developmentally disabled, preadolescent youth. It provides interdisciplinary evaluations of learning disabled children, assures appropriate school recommendations for them, and trains and counsels their parents. Other activities include continuing education workshops for health professionals regarding developmental and other learning disabilities.

TITLE: Transitions in Pediatric Pulmonary Care Training

PRINCIPAL INVESTIGATOR: Elaine Mischler, M.D.
University of Wisconsin at Madison
Department of Pediatrics
600 Highland Avenue
Madison, WI 53792

PHONE NUMBER: (608) 263–8555

PROJECT PERIOD: 10/01/85 – 06/30/90

SUMMARY:

The emphasis of this pediatric pulmonary center is interdisciplinary training in the understanding, approach, ad delivery of effective patient care with the following four critical transition points: Transition from intensive care delivered in a neonatal intensive care unit to the general pediatric unit and ultimately to the general pediatrician or pediatric pulmonologist; transition of the adolescent from pediatrics to the internal medicine care setting; transition of the chronically ill pulmonary patient to the home setting; and transition of the chronically ill child from the home into the community.

TITLE: University Affiliated Center

PRINCIPAL INVESTIGATOR: Mark Swanson, M.D., M.P.H.
University of Texas
Southwestern Medical Center at Dallas
200 Treadway Plaza
Exchange Park
Dallas, TX 75235

PHONE NUMBER: (214) 688–7117

PROJECT PERIOD: 07/01/85 – 06/30/90

SUMMARY:

The University Affiliated Center's activities include inservice and preservice training, development of model projects, technical assistance, research, and dissemination. These activities help it fulfill its mission of improving the quality of life for children with developmental disabilities or chronic illnesses and their families. Responsiveness to national, state and local issues enhance the Center's effectiveness.

TITLE: University Affiliated Cincinnati Center for Developmental Disabilities

PRINCIPAL INVESTIGATOR: Jack H. Rubinstein, M.D.
University of Cincinnati
Pavilion Building
Elland and Bethesda Avenues
Cincinnati, OH 45229

PHONE NUMBER: (513) 559–4688

PROJECT PERIOD: 07/01/85 – 06/30/90

SUMMARY:

This center has a strong clinical service base which provides the foundation for the interdisciplinary training of health and health-related professionals in the diagnosis, treatment, and management of children and adolescents with developmental disabilities and other chronic handicapping conditions. The project provides a variety of experiences to develop knowledge and skills related to health care systems, research, and other relevant topics in order to develop knowledge and behaviors which will impact on the delivery of services. Specialized preservice training programs and continuing education activities are also provided in such areas as genetic counseling for clinical nurse specialists and the nutritional needs of children with chronic illness/handicap.

TITLE: University Affiliated Facility at the University of Kansas Medical Center

PRINCIPAL INVESTIGATOR: Joseph G. Hollowell, Jr., M.D., M.P.H.
University of Kansas Medical Center
39th and Rainbow Boulevard
Kansas City, KS 66103

PHONE NUMBER: (913) 588–5900

PROJECT PERIOD: 07/01/89 – 06/30/94

SUMMARY:

The purpose of this interdisciplinary training program is to prepare professionals for leadership roles in the provision of health and related care of children with chronic handicapping conditions and their families. Leadership preparation includes teaching, research, and administrative training. Practicum sites are available across a continuum of handicapping conditions, levels of functioning, and age ranges to ensure relevancy of training and include hospital, clinic, and community-based programs. Program and resource development with State agencies, including Title V programs, will continue through cooperative planning, training, and service activities.

TITLE: University Affiliated Facility Interdisciplinary Training

PRINCIPAL INVESTIGATOR:
William M. Levinson, M.D.
Westchester County Medical Center
Mental Retardation Institute
216 Cedarwood Hall
Valhalla, NY 10595–1689

PHONE NUMBER: (914) 285–8170

PROJECT PERIOD: 07/01/82 – 06/30/90

SUMMARY:

The overall goals for this project include providing interdisciplinary training and continuing education to a wide range of professionals, and providing exemplary services as a basis for training activities. The interdisciplinary training program is based on a comprehensive curriculum, participation in interdisciplinary and disciplinary clinical services, and individual training plans. Followup data on trainees show that the majority enter either administrative/program or clinical services positions. Other accomplishments have occurred in the areas of exemplary service models, technical assistance and dissemination, consultations, and faculty presentations.

TITLE: University Affiliated Interdisciplinary Training Facility (Miami)

PRINCIPAL INVESTIGATOR:
Robert S. Stempfel, M.D.
Mailman Center for child Development
University of Miami School of Medicine
P.O. Box 016820
Miami, FL 33101

PHONE NUMBER: (305) 547–6635

PROJECT PERIOD: 07/01/89 – 06/30/94

SUMMARY:

The Mailman Center for Child Development is a University Affiliated Program. The primary purpose of the program is to increase the quality and number of professionals in the field of maternal and child health and to prepare them to accept leadership roles in the community. The Mailman Center is a teaching, research, and service institute dedicated to the prevention of handicapping conditions, the prevention of secondary consequences of existing handicaps, and the provision of family-centered, community-integrated services for persons with handicapping conditions and other special health care needs.

TITLE: University Affiliated Training Center (Baltimore)

PRINCIPAL INVESTIGATOR:
Gary Goldstein, M.D.
Johns Hopkins University School of Medicine
Kennedy Institute for Handicapped Children
707 North Broadway
Baltimore, MD 21205

PHONE NUMBER: (301) 550–9483

PROJECT PERIOD: 07/01/85 – 06/30/90

SUMMARY:

The John F. Kennedy Institute for Handicapped Children is a multistate, regional resource center providing advanced professional degree training, exemplary services, internationally recognized research, and community outreach services to children and families. The institute began in 1937 as the Children's Rehabilitation Institute in Reisterstown, Maryland, and moved to its present location at the Johns Hopkins Medical Institutions complex in 1967 when it was first designated as a MCH-funded University Affiliated Facility (UAF). Each year, services are provided to over 6,000 children with a wide range of handicapping conditions.

TITLE: University Affiliated Training Center (Boston)

PRINCIPAL INVESTIGATOR:
Allen Crocker, M.D.
Children's Hospital of Boston
Fegan 10
300 Longwood Avenue
Boston, MA 02115

PHONE NUMBER: (617) 735–6509

PROJECT PERIOD: 07/01/85 – 06/30/90

SUMMARY:

This developmental evaluation clinic/child study center is devoted to the concerns of young persons with mental retardation, other developmental handicaps, chronic illnesses, and/or genetic diseases. Activities include advocacy for young persons with mental retardation or other conditions which impinge on development; strategic, interdisciplinary, preservice education for students; diagnostic assessment, therapeutic program planning, and follow-along services for children (and some adults) who are in particular need of developmental assistance; high quality inservice and continuing education to workers in the field; parent training and public education; technical assistance for relevant programs; and research aimed at improving knowledge and insights.

TITLE:	University Affiliated Training Center (Chapel Hill, NC)
PRINCIPAL INVESTIGATOR:	Melvin Levine, M.D. University of North Carolina at Chapel Hill School of Medicine Chapel Hill, NC 27514
PHONE NUMBER:	(919) 966–1020
PROJECT PERIOD:	07/01/65 – 06/30/90

SUMMARY:

This project provides interdisciplinary training to health care professionals within the context of the provision of exemplary services and clinical research. Contracts drawn with a number of institutions and agencies extend the training base of the division and provide mechanisms for entering into the service community in a programmatic manner. Currently, the project supports five trainees, two postdoctoral (pediatrics and psychology) and three predoctoral (administration, physical therapy, and nutrition).

TITLE:	University Affiliated Training: Multihandicapped Children
PRINCIPAL INVESTIGATOR:	Warren E. Cohen, M.D. Children's Hospital of Los Angeles 4650 Sunset Boulevard Los Angeles, CA 90027
PHONE NUMBER:	(213) 669–2151
PROJECT PERIOD:	07/01/89 – 06/30/94

SUMMARY:

This program provides graduate-level training for professionals who seek advanced training in caring for children and families affected by developmental disability and chronic illness. The training program strongly emphasizes prevention, detection, early intervention, and provision of exemplary and culturally appropriate care delivery. In addition to graduate-level training, the program is engaged in the development and dissemination of related teaching and instructive materials, as well as the provision of consultative services and technical assistance to community and government agencies involved in the care of children and families affected by handicapping conditions.

TITLE: University of Tennessee, Memphis Boling Center for Developmental Disabilities—University Affiliated Program

PRINCIPAL INVESTIGATOR: Gerald Golden, M.D.
University of Tennessee at Memphis
711 Jefferson Avenue
Memphis, TN 38105

PHONE NUMBER: (901) 528–6512

PROJECT PERIOD: 07/01/89 – 06/30/94

SUMMARY:

The center trains personnel representing the following clinical specialties that serve mentally retarded and developmentally disabled populations: Pediatrics, genetics, biochemistry, nutrition, nursing, audiology/speech pathology, social work, psychology, special education, occupational therapy, and physical therapy. It serves as a central resource for program development, information, continuing inservice education, technical assistance, and consultation in the mid-South area.

TITLE: Walsman Center University Affiliated Program

PRINCIPAL INVESTIGATOR: Raymond Chun, Ph.D.
University of Wisconsin at Madison
Waisman Center on Mental Retardation
and Human Development
1500 Highland Avenue
Madison, WI 53705

PHONE NUMBER: (608) 263–7108

PROJECT PERIOD: 07/01/89 – 06/30/94

SUMMARY:

The mission of the Waisman Center University Affiliated Program is to improve the lives of persons with chronic handicapping conditions and their families. In order to do this, the primary goal of the UAP is to provide interdisciplinary training for professionals who will serve persons with handicaps and their families. Other goals include the provision of exemplary clinical/educational services to persons with chronic handicapping conditions, the sharing of the resources of the Waisman Center through outreach activities, and the conduct of research related to human development and chronic handicapping conditions.

TITLE:	Adaptation of the FIM For Use with Infants and Children: Pediatric Evaluation of Disability Inventory
PRINCIPAL INVESTIGATOR:	Stephen Haley, Ph.D. Department of Rehabilitation Medicine Tufts University School of Medicine New England Medical Center 750 Washington St #75K-R Boston, MA 02111
PHONE NUMBER:	(617) 956-5031
PROJECT PERIOD:	03/01/88 – 02/27/91

SUMMARY:

Children with chronic disabling disorders frequently are limited in their age-appropriate functional abilities. Much work has recently gone into the development of standardized uniform minimal systems of functional assessments for adults with disabilities and handicaps (e.g., the FUNCTIONAL INDEPENDENCE MEASURE). These instruments, however, are not useful for disabled children below age seven, and no other similar functional independence tool that is sensitive to developmental issues exists for infants and toddlers. The goal of this is to create a new instrument (PEDIATRIC EVALUATION OF DISABILITY INVENTORY) that is appropriate for infants, toddlers, and small children. Through the addition of developmentally relevant content, the items of the FIM will be revised. The test will then be standardized on a normative sample of infants and children and these data will be further analyzed to support the quality of the test in technical requirements such as reliability, validity, and precision. At the conclusion of this project, a diagnosis-independent method of measuring the functional status and progress of infants, toddlers, and small children will be available. Through the development of test and instruction manuals, training packages for professionals, and computer software to assist in scoring the test, wide dissemination and utilization of the Pediatric Evaluation of Disability Inventory will be achieved.

TITLE: Development of Mania Rating Scales for Children Age 6–12

PRINCIPAL INVESTIGATOR: Mary A. Fristad, Ph.D.
The Ohio State University
Division of Child/Adolescent Psychiatry
N217 Upham Hall
473 W. 12th Avenue
Columbus, OH 43210–1228

PHONE NUMBER: (614) 293–8235

PROJECT PERIOD: 09/89 – 02/91

SUMMARY:

Bipolar disorder or mania has only recently been recognized as an authentic psychiatric disorder in prepubertal populations. Lack of standardized assessment tools has hampered research on care delivered to children with bipolar disorder in clinical settings. The purpose of Dr. Fristad's study is to develop more precise assessment instruments that can be used to improve clinical management of bipolar children and facilitate research on the efficacy of services provided to these children. The research subjects are 90 children aged 6–12 years at time of initial evaluation and their parents. Subjects include children with mixed or manic type bipolar disorder, children with other psychiatric disorders that are often confused with bipolar disorder, and children with no psychiatric diagnosis.

TITLE:	NICU Care for VLBW Infants
PRINCIPAL INVESTIGATOR:	Susan Leib, Ph.D. Children's Hospital Medical Center of Akron 281 Locust Street Akron, OH 44308
PHONE NUMBER:	(216) 379-8290
PROJECT PERIOD:	9/1/90 – 8/30/91

SUMMARY:

The overall purpose of this project is to conduct an investigation of the immediate and long-range effects of using Neonatal Individualized Developmental Care and Assessment Programming (NIDCAP) with preterm neonates at risk for chronic lung disease and poor neurological and developmental outcome who have been hospitalized in a Level III transport (outborn) NICU that uses standard conventional nursing for care of sick infants. NIDCAP procedures have shown promising results when implemented through a research model with at-risk infants in a Level III inborn NICU, using a primary nursing model of care (Als, et al., 1986) but have not been tested in other situations.

A repeated measures design will be used to determine the immediate and long-range effects of providing NIDCAP intervention. A total of 60 infants who meet study criteria will be randomly assigned to experimental and control groups. Experimental infants will receive observational assessments, every 7 days beginning by the 5th day of hospitalization, upon which written Individual Developmental Care Plans (IDCP) will be developed and charted by one of four trained nurses. In addition, each infant will be assigned for care to at least one study nurse across each three daily care shifts who will implement intervention and work with families in incorporating procedures into their interactions with their infant. Intervention will continue until the infant's discharge when it will be linked, through an individual Family Service Plan (IFSP), to the Neonatal Follow-Up Clinic and other community resources that may be needed by the family or infant following discharge. Planned transitions will be implemented by a designated case manager.

All experimental and control group infants will be followed longitudinally at 6, 12, and 24 months EDC (corrected age) through the Neonatal Follow-Up Clinic. Standard medical and developmental measures will be implemented during these visits. In addition, all families and their study infants will receive additional assessments at term (40 weeks corrected age), 2 weeks post-term (42 weeks corrected age), and 4 weeks post-term (44 weeks corrected age) and at each of the Follow-Up Clinic points. These data will be analyzed to determine the immediate and long-range effects of NIDCAP on medical outcome, infant behavioral outcome, and family outcome measures.

TITLE: Operational Definition of Independence

PRINCIPAL INVESTIGATOR: Marcus Fuhrer, Ph.D.
Research and Training Center—
Independent Living
3400 Bissonnett – Suite 101
Houston, TX 77005

PHONE NUMBER: (713) 666–6244

PROJECT PERIOD:

SUMMARY:

This project is designed to develop an operational definition of independence that incorporates three dimensions of the term: perceptions of control over one's life, psychological factors, and behavioral or functional characteristics. The objective is to develop an assessment instrument to quantify an individual's independence in each of the above domains.

TITLE: Pediatric Cardiac Care Quality Assurance Consortium

PRINCIPAL INVESTIGATOR: James H. Moller, M.D.
Corporation for the Advancement of
Pediatric Cardiac Services
Box 288 UMHC
420 Southeast Delaware Street
Minneapolis, MN 55455

PHONE NUMBER: (612) 626–2790

PROJECT PERIOD: 07/01/87–06/30/90

SUMMARY:

This project will develop severity-adjusted outcome standards for the major pediatric cardiac surgical procedures and a review protocol which incorporates these outcome standards. This system will then be incorporated into the ongoing quality assurance programs of pediatric cardiac centers and serve as a model for individual cardiac centers across the Nation.

TITLE: Standardized Assessment of Behavioral and Emotional Problems of SED and LD Children

PRINCIPAL INVESTIGATOR: Stephanie H. McConaughy, Ph.D., PI.
University of Vermont
Department of Psychiatry
One South Prospect Street
Burlington, VT 05401

PHONE NUMBER: (802) 656–4563

PROJECT PERIOD: 09/01/88 – 08/31/91

SUMMARY:

This research is designed to compare the competencies and behavioral and emotional problems of 6- to 16-year-old children designated as Seriously Emotionally Disturbed (SED) or Learning Disabled (LD) according to criteria defined by PL 94-142 (Education of the Handicapped Act, 1977, 1981). The project utilizes two standardized rating scales developed by one of the investigators: the Child Behavior Checklist (CBCL) and Teacher Report Form (TRF). A History Form developed for the project also requests data on children's history of special education services, standardized ability and achievement test scores, and psychiatric diagnoses. Subjects will consist of children identified as SED or LD by Basic Staffing Teams according to the state regulations interpreting PL 94-142. We have obtained similar data on SED and LD children in Vermont, Pennsylvania, Florida, Michigan, Colorado, and Nebraska. The SED and LD subjects will be matched to the normative samples for the CBCL and TRF and to a sample of children referred for mental health services. All samples will be matched on sex and age.

Specific objectives of the research are: 1) to compare patterns of behavioral and emotional problems of SED and LD children obtained from standardized ratings from parents and teachers; 2) to compare the severity of problems of SED and LD children to those of normative samples of the same age and sex; 3) to compare the severity of problems of SED and LD children to those of clinically referred children of the same age and sex; 4) to identify differences in the severity and patterns of problems that discriminate SED from LD children; 5) to identify differences in competencies and school adaptive functioning that discriminate SED from LD children; 6) to identify differences in academic achievement and cognitive ability that discriminate SED from LD children; and 7) to test effects of age, sex, socioeconomic status, and state of residence on the patterns and severity of problems of SED and LD children.

TITLE: Standardized Interviews for Seriously Emotionally Disturbed Children

PRINCIPAL INVESTIGATOR: Thomas Achenbach, Ph.D.
University of Vermont
Department of Psychiatry
One South Prospect Street
Burlington, VT 05401

PHONE NUMBER: (802) 656–4563

PROJECT PERIOD: 09/01/90 – 08/31/93

SUMMARY:

The purpose of this research is to test the validity of a standardized clinical interview for discriminating Seriously Emotionally Disturbed (SED) children from Learning Disabled (LD) and normal children. This project builds upon the investigators' current research on empirically based assessment of the competencies and behavioral/emotional problems of SED and LD children. The project utilized three standardized measures developed by the investigators: the Semistructured Clinical Interview for Children (SCIC), the Child Behavior Checklist (CBCL), and Teacher's Report Form (TRF).

The SCIC will be administered to 72 SED, 72 LD, and 72 normal children aged 6–11 years. We will also obtain the CBCL from one parent and the TRF from one teacher of each subject. We will then test the discriminative power of combined scores from the SCIC, CBCL, and TRF for distinguishing SED children from LD and normal children of the same age and sex. If successful, the multiaxial, empirically based approach will provide a means for obtaining standardized, objective assessment of SED children that has not been possible through other traditional evaluation procedures. Specific objectives of the proposed research are: 1) to examine the patterns of behavioral/emotional problems of SED and LD children exhibited during a standardized clinical interview; 2) to compare the severity of problems of SED and LD children shown in the clinical interview with those of normal children of the same age and sex; 3) to identify differences in the severity and patterns of problems shown in the clinical interview that discriminate SED from LD children; 4) to compare the severity and patterns of problems of SED and LD children shown in the clinical interview with problems reported by parents and teachers; 5) to test the power of combined scores obtained from the clinical interview, parent reports, and teacher reports for discriminating SED, LD, and normal children; and 6) to test the effects of age, sex, SES, and IQ on the patterns and severity of problems of SED and LD children.

TITLE: A National Study of State Legislation for Family Support Programs

PRINCIPAL INVESTIGATOR:

H. Rutherford Turnbull III
Beach Center on Families and Disability
3111 Haworth
The University of Kansas
Lawrence, KS 66045

PHONE NUMBER: (913) 864–7600

PROJECT PERIOD: 07/01/90 – 06/30/91

SUMMARY:

Many states now have family support policies and programs (services directly to families with members with disabilities). Nearly half of the states do not. Yet the professional literature on people with disabilities and their families, and the expressed needs of many families via their organizations, show that family support policies and programs are desirable and effective. Notwithstanding the progress and need, there is no single source that states can use to identify the content, justification, and effectiveness of state legislation authorizing family support programs. This research analyzes all of the family-support legislation in all of the states, the family-support regulations of nearly half of the states that have such legislation, and the justifications for and effectiveness of family support policy and laws. By bringing together in a single model statute the legal and policy research, the Beach Center will make it possible for states to adopt or improve family support policies and programs and thus to know how best to respond to the expressed needs for family support policy, law, and programs. This project has:

- Nearly completed a thorough review of all of the literature on family support within and without the disability field;
- Nearly completed a definitive policy analysis of family support; drafted a model family support statute based on the literature review and the policy analysis;
- Analyzed the family support laws of all states that have family support legislation; cross-referenced the provisions of the model statute to comparable provisions of the laws of all states with family support legislation and to the regulations of many of those states;
- Drafted a document that combines the literature review, policy analysis, model statute, and legislative research for dissemination to state governments and family-disability and professional organizations, indicating the nature of the work and how it may be used.

This project will:

- Complete the documents identified above by November 1, 1990;
- Disseminate them to family organizations, professionals, state government organizations, and legislatures.

TITLE: Analysis of State Policies Which Impact on Children/Youth with Disabilities

PRINCIPAL INVESTIGATOR: Abigail English, J.D.
Center for Children with Chronic Illness and Disability
Box 721 UMHC
Minneapolis, MN 55455

PHONE NUMBER: (612) 626–4032

PROJECT PERIOD: 1989 – 1994

SUMMARY:

1. What are the gaps in eligibility and coverage in federal and state programs which present obstacles for chronically ill and disabled children seeking comprehensive services in a setting most appropriate to their needs?
2. What policy and/or practice changes would be needed to address these obstacles and improve access of children with chronic illnesses and disabilities to services they need?

A comprehensive analysis of state and federal programs that offer services to children with chronic illness or disability will be undertaken to: a) determine eligibility criteria and coverage limitations of each program; b) analyze relationships among programs in order to identify gaps and barriers for those seeking access; and c) describe model proposals designed to overcome barriers and gaps in services. These results will aid parents and their children with chronic conditions, service providers, and policy makers in their efforts to reduce barriers and make coordinated services more available.

TITLE:	Barriers to Appropriate Services: Legal Framework for Financing (1)
PRINCIPAL INVESTIGATOR:	Abigail English, J.D. Center for Children with Chronic Illness and Disability Box 721 UMHC Minneapolis, MN 55455
PHONE NUMBER:	(612) 626–4032
PROJECT PERIOD:	1989 – 1994

SUMMARY:

1. To what extent does existing law provide a basis for appropriate and effective participation in decision-making by older children with chronic illness and disabilities?
2. What are the legal barriers to participation in decision-making by older children and youth with chronic illness and disabilities?
3. What model policies can be enacted at the state level that would facilitate such participation?

The purpose of this study is to: a) clarify the existing legal framework for decision-making for youth with chronic illness or disability; b) determine the legal barriers to participation in decision-making by youths with chronic conditions. The results of this study will assist professionals working with youth and policy makers in developing policies which will reduce barriers to participation in youth decision-making.

Identification of the key federal and state financing programs to be analyzed is nearly complete. Detailed analysis of one program (EPSDT under Medicaid) is underway, examining state implementation of federal requirements.

TITLE: Barriers to Appropriate Services: Legal Framework for Financing (2)

PRINCIPAL INVESTIGATOR:
Abigail English, J.D.
Center for Children with Chronic Illness and Disability
Box 721 UMHC
Minneapolis, MN 55455

PHONE NUMBER: (612) 626–4032

PROJECT PERIOD: 1989 – 1994

SUMMARY:

1. What are the gaps in eligibility and coverage in federal and state programs which present obstacles for chronically ill and disabled children seeking comprehensive services in a setting most appropriate to their needs?
2. What policy and/or practice changes would be needed to address these obstacles and improve access of children with chronic illness and disabilities to services they need?

The literature review identifying key federal programs and key states with model laws is nearly complete. Pertinent case law is being identified.

TITLE: Center for Rural Mental Health Care Research

PRINCIPAL INVESTIGATOR:
Richard G. Smith, M.D.
University of Arkansas/Medical Science
Psychiatry & Behavioral Sciences
4301 W. Markham, Slot 554
Little Rock, AR 72205

PHONE NUMBER: (501) 686–5600

PROJECT PERIOD: 09/90 – 08/93

SUMMARY:

This Center provides an interdisciplinary environment in which to address major policy and service issues related to provision of rural mental health care. The ultimate goal of the Center is to use research as a means of improving clinical mental health care for rural populations by addressing issues of access, utilization, effectiveness, and outcome. Using the rural diversity present in the State of Arkansas as a natural laboratory, the Center is emphasizing three areas of research: (1) assessment of rural child and adolescent mental health, (2) development of a rural schizophrenia registry from information contained in Veterans Administration, Medicaid, and state mental hospital files, and (3) mental health care for rural elderly with cognitive impairment.

TITLE: Costs and Outcomes for Chronically Ill Children: A Policy Analysis

PRINCIPAL INVESTIGATOR: Peggy McManus, M.H.S.
Center for Children with Chronic Illness and Disability
Box 721 UMHC
Minneapolis, MN 55455

PHONE NUMBER: (612) 626–4032

PROJECT PERIOD:

SUMMARY:

1. Prepare a policy option paper summarizing current applications and findings from cost-effectiveness analyses, employer/insurer innovations in managing high cost illness, and recommendations for improving public and private financing of alternative placement options.
2. Design a cost-effectiveness data collection component to be used in assessing the costs and effects of care provided to children with special health needs in alternative placements.
3. Provide consultation to the University of Minnesota on the collection and analysis of the cost-effectiveness data.
4. Offer training and technical assistance regarding recommended strategies for selecting, evaluating, and financing cost-effective placement alternatives.

A literature review on managing high cost illness from the employer/payor perspective has been done. Analyses are underway examining multiple issues (types of illnesses, screening/tracking methods used, cost control innovations, results, etc.). A policy paper identifying strategies relevant for high cost pediatric illnesses is being prepared with recommendations for improvements.

TITLE: Reasonable Efforts in Permancy Planning

PRINCIPAL INVESTIGATOR: Christopher Petr, Ph.D.
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3111 Haworth
The University of Kansas
Lawrence, KS 66045

PHONE NUMBER: (913) 864–7600

PROJECT PERIOD: 07/01/90 – 06/30/91

SUMMARY:

Children with disabilities often seem to be high risks for out-of-home placement. This project will develop a state-of-the-art definition of "reasonable efforts" to maintain children with emotional disorders (ED), developmental disabilities (DD), and technology support (TS) in permanent placements in the least restrictive environment. The overall research question is: What state policies, programs, supports, and values regarding "reasonable efforts" are the most conducive to maintaining those children with emotional disorders, developmental disabilities, and technology support in the least restrictive, most home-like environments?

To answer this question, we will investigate two aspects of this issue during the first two years of the project. The first involves a policy analysis of one exemplary state's current "reasonable efforts." The second centers on understanding the stresses faced by families and the match between their needs and the same state's "reasonable efforts."

This project has:

- Begun data collection and analysis.

This project will:

- Complete data collection and analysis;
- Initiate educational and other change efforts to achieve implementation of the state-of-the-art definition of "reasonable efforts" in one or two targeted states;
- Work with family organizations, service providers, and policy makers;
- Submit the policy analysis for publication in a peer-reviewed journal;
- Prepare a manual on change efforts for family organizations;
- Present the content of the manual at annual meetings of family and provider organizations.

Health Care Expenses

TITLE: A Study of Financing Options for Community and Home-Based Treatment

PRINCIPAL INVESTIGATOR:
Krista Kutash, M.B.A.
Research and Training Center for Children's Mental Health
University of Southern Florida
Florida Mental Health Institute
13301 Bruce B. Downs Boulevard
Tampa, FL 33612

PHONE NUMBER: (813) 974–4500

PROJECT PERIOD: 09/27/89 – 09/28/94

SUMMARY:

The purpose of this project is to identify the financing options that could be used to serve children and adolescents with serious emotional disturbances and their families, and to study the fiscal incentives and disincentives to community and home-based treatment.

TITLE: Barriers to Appropriate Services: Legal Framework for Financing (11)

PRINCIPAL INVESTIGATOR:
Abigail English, J.D.
Center for Children with Chronic Illness and Disability
Box 721 UMHC
Minneapolis, MN 55455

PHONE NUMBER: (612) 626–4032

PROJECT PERIOD: 1989 – 1994

SUMMARY:

1. To what extent does existing law provide a basis for appropriate and effective participation in decision-making by older children with chronic illness and disabilities?
2. What are the legal barriers to participation in decision-making by older children and youth with chronic illness and disabilities?
3. What model policies can be enacted at the state level that would facilitate such participation?

The purpose of this study is to: a) clarify the existing legal framework for decision-making for youth with chronic illness or disability; b) determine the legal barriers to participation in decision-making by youths with chronic conditions. The results of this study will assist professionals working with youth and policy makers in developing policies which will reduce barriers to participation in youth decision-making.

Identification of the key federal and state financing programs to be analyzed is nearly complete. Detailed analysis of one program (EPSDT under Medicaid) is underway, examining state implementation of federal requirements.

TITLE: Barriers to Appropriate Services: Legal Framework for Financing (2)

PRINCIPAL INVESTIGATOR: Abigail English, J.D.
Center for Children with Chronic Illness
and Disability
Box 721 UMHC
Minneapolis, MN 55455

PHONE NUMBER: (612) 626–4032

PROJECT PERIOD: 1989 – 1994

SUMMARY:

1. What are the gaps in eligibility and coverage in federal and state programs which present obstacles for chronically ill and disabled children seeking comprehensive services in a setting most appropriate to their needs?
2. What policy and/or practice changes would be needed to address these obstacles and improve access of children with chronic illness and disabilities to services they need?

The literature review identifying key federal programs and key states with model laws is nearly complete. Pertinent case law is being identified.

TITLE: Costs and Outcomes for Chronically Ill Children: A Policy Analysis

PRINCIPAL INVESTIGATOR: Peggy McManus, M.H.S.
Center for Children with Chronic Illness and Disability
Box 721 UMHC
Minneapolis, MN 55455

PHONE NUMBER: (612) 626–4032

PROJECT PERIOD:

SUMMARY:

1. Prepare a policy option paper summarizing current applications and findings from cost-effectiveness analyses, employer/insurer innovations in managing high cost illness, and recommendations for improving public and private financing of alternative placement options.
2. Design a cost-effectiveness data collection component to be used in assessing the costs and effects of care provided to children with special health needs in alternative placements.
3. Provide consultation to the University of Minnesota on the collection and analysis of the cost-effectiveness data.
4. Offer training and technical assistance regarding recommended strategies for selecting, evaluating, and financing cost-effective placement alternatives.

A literature review on managing high cost illness from the employer/payor perspective has been done. Analyses are underway examining multiple issues (types of illnesses, screening/tracking methods used, cost control innovations, results, etc.). A policy paper identifying strategies relevant for high cost pediatric illnesses is being prepared with recommendations for improvements.

TITLE: Mental Health Service Utilization by Children and Parents

PRINCIPAL INVESTIGATOR: Herbert Schlesinger, Ph.D.
Graduate Faculty
New School for Social Research
65 Fifth Avenue, Room 341
New York, NY 10003

PHONE NUMBER: (617) 956–5031

PROJECT PERIOD: 09/89 – 08/91

SUMMARY:

Few empirical research data are currently available on use of mental health services by children and adolescents enrolled in large health insurance plans. The overall goal of this research is to investigate and document patterns of utilization of mental health services by 45,000 children and adolescents and their parents in the Blue Cross/Blue Shield Federal Employee Program (FEP) during the 10-year period 1974–1983. The investigators are also examining utilization of other types of medical care, ratios of inpatient to outpatient services, and service costs. The study builds on prior NIMH-supported research (RO1MH40479) by Dr. Schlesinger and colleagues and utilizes database previously assembled from FEP claims and enrollment files and the Office of Personnel Management (OPM) files.

TITLE: Screening Impact on Services & Costs for Foster Children

PRINCIPAL INVESTIGATOR: John Landsverk, Ph.D.
Department of Sociology
San Diego State University
5178 College Avenue
San Diego, CA 92182-1900

PHONE NUMBER: (619) 594–5449

PROJECT PERIOD: 09/89 – 08/93

SUMMARY:

This research is examining the effect of providing child mental health status screening information to case management social workers in a large urban public foster care system. The aim is to ascertain how routine provision of such information affects recognition of mental health problems, referral for assessment and treatment, use of mental health services, cost of these services, and child outcomes. The study is being conducted collaboratively by researchers located at San Diego State University, the San Diego County Departments of Social Services and Mental Health, and Children's Hospital–San Diego.

TITLE: Survey of Health Care Utilization and Family Out-of-Pockets Expenses

PRINCIPAL INVESTIGATORS:
Paul Newacheck, M.P.P.
Peggy McManus, M.H.S.
Center for Children with Chronic Illness and Illness
Box 721 UMHC
Minneapolis, MN 55455

PHONE NUMBER: (612) 626–4032

PROJECT PERIOD: 1991 – 1994

SUMMARY:

This component of the longitudinal study is designed to provide new information on the costs incurred by families in caring for a chronically ill child. Through a mail-out survey of over 500 families conducted at regular intervals, the project will collect information on direct costs such as out-of-pocket expenses for hospital care, and indirect costs such as the value of lost parental employment opportunities. In addition, information will be collected on utilization of a range of health services by chronically ill children. These data will permit us to draw a relatively complete profile of the utilization and expenditure patterns for a fairly large sample of chronically ill children.

The project will also collect information on health insurance coverage. This information will be used to assess how health insurance influences use of services and family out-of-pocket expenses. Included also will be survey questions concerning perceptions of financial and insurance barriers to receiving needed health care services designed to elicit degree of worry or concern about health care bills. The goal of the project is to establish a database that can be used to address several key public policy issues, including:

Health Care Utilization Patterns

1. What services do chronically ill children use?
2. How does service use vary by age, severity, and diagnosis?
3. How do utilization patterns of chronically ill children compare to those of children without chronic conditions?

Direct Costs of Caring for Chronically Ill Children

1. What is the range of family out-of-pocket expenses for caring for a chronically ill child?
2. How do these expenditures vary by age, severity, and diagnosis?
3. How many families experience out-of-pocket expenses in excess of 5, 10, or 15 percent of their family income over the course of the year?
4. Which types of health care services lead to high out-of-pocket expenses?

Chronic Illness and Disabilities/ Injury and Trauma/Rehabilitation

TITLE: A Longitudinal Study of Children With Chronic Illness and Disability

PRINCIPAL INVESTIGATORS:
Robert Wm. Blum, M.D., M.P.H., Ph.D.
Joan Patterson, Ph.D.
Center for Children with Chronic Illness and Disability
Box 721 UMHC
Minneapolis, MN 55455

PHONE NUMBER: (612) 626–4032

PROJECT PERIOD: 1990 – 1994

SUMMARY:

1. What are the individual child (e.g., personality, developmental), disease-specific, familial (e.g., composition, interactive styles) and environmental (e.g., school, neighborhood) factors associated with resilience and optimal psychosocial outcomes for children and youth with chronic illness and disability?
2. What are the interactive effects between the key predictor variables of optimal psychosocial outcomes?
3. How do the predictive variables and interactions change over time as the child matures, the family and/or environments change, and/or the condition itself fluctuates?

Two age cohorts of children (birth–2 years and 8–10 years) who are newly diagnosed with a chronic illness or disability (e.g., cystic fibrosis, spina bifida, mental retardation) and their families will be followed for five years. The goal of the study is to identify those individual, familial, and environmental risk and protective factors associated with competence and well-being. Conditions selected will allow examination of the differential impact of visible vs. invisible conditions, cognitive vs. physical impairment, and progressive vs. uncertain or stable illness course on child and family outcomes. In addition, the study will explore how these factors interact and change over time as the child matures, the condition fluctuates, the family changes, and/or the environmental context changes. Identification of the risk and protective factors associated with competent child and family functioning will lead to demonstration programs and intervention studies designed to promote resilience in children with disabilities and their families, the focus of the study is on the psychosocial impact of chronic illness and not specific conditions.

Cooperation is being solicited from all hospitals and pediatricians treating children in Minnesota's seven-county Metro area and Washington's three-county Metro area and procedures for identifying subjects are being established. Sample selection and time of diagnosis are within six months from time of diagnosis. The first draft of the entire research protocol has been developed and is under review by investigators. Human subjects approval has been received. Piloting of research protocol with families will take place in October and data collection will commence in November of 1990.

TITLE: A National Study of State Legislation for Family Support Programs

PRINCIPAL INVESTIGATOR: H. Rutherford Turnbull III
Beach Center on Families and Disability
3111 Haworth
The University of Kansas
Lawrence, KS 66045

PHONE NUMBER: (913) 864–7600

PROJECT PERIOD: 07/01/90 – 06/30/91

SUMMARY:

Many states now have family support policies and programs (services directly to families with members with disabilities). Nearly half of the states do not. Yet the professional literature on people with disabilities and their families, and the expressed needs of many families via their organizations, show that family support policies and programs are desirable and effective. Notwithstanding the progress and need, there is no single source that states can use to identify the content, justification, and effectiveness of state legislation authorizing family support programs. This research analyzes all of the family-support legislation in all of the states, the family-support regulations of nearly half of the states that have such legislation, and the justifications for and effectiveness of family support policy and laws. By bringing together in a single model statute the legal and policy research, the Beach Center will make it possible for states to adopt or improve family support policies and programs and thus to know how best to respond to the expressed needs for family support policy, law, and programs. This project has:

- Nearly completed a thorough review of all of the literature on family support within and without the disability field;
- Nearly completed a definitive policy analysis of family support; drafted a model family support statute based on the literature review and the policy analysis;
- Analyzed the family support laws of all states that have family support legislation; cross-referenced the provisions of the model statute to comparable provisions of the laws of all states with family support legislation and to the regulations of many of those states;
- Drafted a document that combines the literature review, policy analysis, model statute, and legislative research for dissemination to state governments and family-disability and professional organizations, indicating the nature of the work and how it may be used.

This project will:

- Complete the documents identified above by November 1, 1990;
- Disseminate them to family organizations, professionals, state government organizations, and legislatures.

TITLE: An Evaluation of Family and LEA Decisions Regarding the Appropriate Placement of Children with Technology Support

PRINCIPAL INVESTIGATOR: Pat Barber, Ph.D.
Beach Center on Families and Disability
3111 Haworth
The University of Kansas
Lawrence, KS 66045

PHONE NUMBER: (913) 864–7600

PROJECT PERIOD: 07/01/90 – 06/30/91

SUMMARY:

As an increasing number of children supported by medical technology move from the confines of health care institutions to home and community settings, school systems and families are beginning to face the challenge of providing appropriate educational services to meet the unique needs of these students. Service provision as well as the appropriate integration of many of these children into educational settings will depend on the resolution of such issues as health care costs, liability, personnel training, assessment, and the coordination of health, education, family, and related service systems. Current educational and health policies provide minimal guidance in addressing these and other factors affecting placement and the provision of services. To date, there is limited information on how service and placement decisions are made for these students. This project has:

- Completed and disseminated an Annotated Bibliography and completed and disseminated a literature review on educational services to children who are chronically ill and technology-supported;
- Contacted or interviewed by telephone over 60 parents and professionals across the country who have experience working with children who are ventilator-assisted in order to gather information about the characteristics and service needs of these children and the educational services issues related to this population;
- Conducted pilot interviews with parents of children who are ventilator-assisted, physicians, and educators as a means of confirming and supplementing information on educational service issues reported in the literature and through telephone contacts.

This project will:

- Conduct research on the factors affecting educational placement and service decisions through surveys and interviews with families of children who are ventilator-assisted and LEAs serving these children in at least six states;
- Disseminate research results through the development of a research monograph, journal articles aimed at special educators, school administrators, and school health personnel, and a handbook of "how-to" articles on practical information for families who participate in educational decisions.

TITLE: Back Injury Study

PRINCIPAL INVESTIGATOR: Jerry H. Wang, Ph.D.
University of Hawaii at Manoa
John A. Burns School of Medicine
Pacific Basin Rehabilitation Research and Training Center
226 North Kuakini Street, #233
Honolulu, HI 96817

PHONE NUMBER: (808) 537–5986
(808) 537–8691 (FAX)

PROJECT PERIOD: 03/91 – 02/94

SUMMARY:

Background: The Department of Labor and Industrial Relations in Hawaii has reported that the back is the most frequently affected body part in industrial accidents. Available information on back injuries is limited to general descriptions. Information on the relationships among injury specifics, treatments, and employment outcomes after back injury is not available.

Purpose: This pilot study for work-related back injuries in the State of Hawaii will: a) investigate the employment outcomes, treatments, and costs of back injury; and b) establish profiles of clients. This project is a positive collaborative working relationship between PBRRTC and the Hawaii State Department of Labor and Industrial Relations and the interest of private insurers.

Methods: Research tasks involved in the examination of selected variables associated with employment-related back injury and the effects rehabilitation has on employment outcomes and costs in Hawaii. Utilizing data collected by the Department of Labor and Industrial Relations from workers' compensation forms and rehabilitation counselors' reports, the relationships among the variables previously mentioned will be determined and profiles of clients will be established. Initial research results will be designed to assist those treating and counseling injured workers as well as organizations that plan, purchase, and provide treatments.

TITLE: Developing Nutrition Services for Children with Special Health Needs

PRINCIPAL INVESTIGATOR: Janice M. Dodds, Ed.D., R.D.
New York State Department of Health and Research, Inc.
Bureau of Nutrition
Corning Towers, Room 859
Albany, NY 12237

PHONE NUMBER: (518) 473–8286

PROJECT PERIOD: 10/01/86 – 09/30/90

SUMMARY:

This project seeks to demonstrate the potential for improved growth and nutrition practices among chronically ill and handicapped children in New York State through the provision of comprehensive and coordinated nutrition care services. Activities include assessing the needs of parents and caretakers, monitoring service delivery, documenting the nutrition problems of the target populations, participating in a regional advisory committee, providing parent and professional education, and providing services to children enrolled at affiliated sites.

TITLE: Exercise and Recreation as Rehabilitation Strategies

PRINCIPAL INVESTIGATOR:
Joyce Varney, Dr.P.H.
University of Hawaii at Manoa
John A. Burns School of Medicine
Pacific Basin Rehabilitation Research and Training Center
226 North Kaukini Street, #233
Honolulu, HI 96817

PHONE NUMBER:
(808) 537–5986;
(808) 531–8691 (FAX)

PROJECT PERIOD: 03/91 – 02/94

SUMMARY:

Background: The islands in the Pacific Basin provide a unique environment for exercise and recreation which are now recognized as important factors in: a) reducing the risk of cardiovascular disease, b) preventing obesity, and c) improving the quality of life for able-bodied persons. Few studies have researched questions about the proper type and intensity of exercise/recreation and their long-term benefits for persons with disabilities.

Purpose: Increase understanding of how exercise (in the unique context of the Pacific Basin) can impact on persons with disabilities.

Methods:

1. A cross-sectional investigation of the health status of persons using wheelchairs focusing on exercise capacity and health status: subjects were divided into two groups, those actively engaged in exercise and those who were active or sedentary.
2. Comparison of Japanese and American wheelchair marathon athletes: a survey of training and dietary habits.
3. Descriptive study (pilot) of persons served in a transitional (rehabilitation hospital to community) therapeutic recreation program: a multi-agency collaborative effort (i.e., PBRRTC, Rehabilitation Hospital of the Pacific, University of Hawaii, Physical Education and Recreation, and Honolulu Department of Parks and Recreation).
4. Investigation of the benefits of exercise: comparing persons with neuromuscular disabilities and walk/jog, swim, cycle, or do not exercise. Factors examined include: type of exercise, physiological measures, pain, and fatigue.

TITLE: Family Perceptions Project

PRINCIPAL INVESTIGATOR: Jean Ann Summers, Ph.D.
Kansas University Affiliated Program
Bureau of Child Research
University of Kansas
Lawrence, KS 66045

PHONE NUMBER: (913) 864–4950

PROJECT PERIOD: Project completed 09/14/90

SUMMARY:

Research suggests that families' perceptions of their children with disabilities have a strong relationship to their ability to cope with the challenges of raising their child. The purpose of this study was to develop and validate measures of the use of four specific coping strategies suggested by cognitive adaptation theory: identifying a cause of the disability, perceiving positive benefits of the child, making comparisons with others, and having a sense of mastery or control of the situation. Measures were developed and field tested with 300 parents of children with and without disabilities. These results were factor analyzed and the revised, shorter instruments were completed by a sample of 1,262 parents of children with disabilities in 34 states.

The results suggest that three of the four instruments (positive contributions, social comparisons, and causal attributions) are internally consistent and show correlations in the expected directions between selected factors on the instruments and parents' feelings of stress and self-esteem. The mastery questionnaire showed results opposite the expected direction (high positive correlations of personal control with stress); follow-up interviews with a sample of respondents suggest this instrument may have been tapping a different construct (sense of responsibility, rather than sense of control). Data are currently being analyzed to identify differences in responses among families of younger and older children, levels of severity of the child's disability, and mothers versus fathers. Future research will focus on continuing the revision and validation of these instruments, measuring and comparing professional perceptions of parents' cognitive coping strategies, and developing interventions to teach families effective use of these coping strategies.

TITLE: Family Reorganization

PRINCIPAL INVESTIGATOR: Joan Patterson, Ph.D.
Center for Children with Chronic Illness
and Disability
Box 721 UMHC
Minneapolis, MN 55455

PHONE NUMBER: (612) 626–4032

PROJECT PERIOD: 1991 – 1994

SUMMARY:

1. How does the family reorganize itself following diagnosis or onset of the condition so as to incorporate the demands of the illness/disability into family life (while still attending to other family needs) and restore balanced functioning to the family system?
2. How does the family reorganize itself at critical developmental transitions to facilitate age-appropriate levels of independence and self-care in the disabled child or adolescent?
3. What are the factors associated with social competence in various settings?

The diagnosis of chronic illness or disability disrupts normal family processes. In this study, qualitative methods (home observations and laboratory tasks) will be used to describe how families reorganize their internal structure to successfully manage the cognitive, behavioral, and emotional tasks associated with the chronic illness or disability while simultaneously meeting the needs of all family members. Families will be studied at the time of diagnosis and at other critical developmental milestones when reorganization is called for. These findings will contribute to better programs and interventions designed to support successful child and family adaptation.

TITLE: Family Support Programs

PRINCIPAL INVESTIGATOR: H. Rutherford Turnbull III
Beach Center on Families and Disability
3111 Haworth
The University of Kansas
Lawrence, KS 66045

PHONE NUMBER: (913) 864–7600

PROJECT PERIOD: 07/01/90 – 06/30/91

SUMMARY:

Although many states and local service providers operate family support programs, there have been only a few evaluations of the effectiveness of those programs. Significantly, none of the evaluations have been from the perspective of the families receiving family support services. Thus, no state or local operator can be sure concerning the effect of those programs on families and thus how to improve the programs. This research project evaluates family support programs from families' perspectives, based on the articulation goals, strategies, and underlying principles of the program.

This project will:

- Identify family support projects to be evaluated;
- Evaluate them from the perspectives of the families receiving services and on the basis of the articulated goals, strategies, and underlying values of the programs themselves;
- Conduct a thorough review and analysis of evaluation literature on family support;
- Prepare a report of the research/evaluation and a critique and analysis of the other evaluation literature; on the basis of the report, propose methods for improving family support programs;
- Disseminate the report and proposals for program improvement to the profession via peer-reviewed articles, to state and local providers (and to their national organizations) via direct mailing, and to the family-disability audience via families' organizations.

TITLE: Injury Recovery Study: Infants and Preschool Children

PRINCIPAL INVESTIGATOR:
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Department of Rehabilitation Medicine
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New England Medical Center
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#75K–R
Boston, MA 02111

PHONE NUMBER: (617) 956–5031

PROJECT PERIOD: 01/01/88 – 12/31/92

SUMMARY:

Given the rapid development characteristics of the first five years of life, it is likely that trauma to the nervous and musculoskeletal systems may result in a clinical course unique to this age group. However, the long-term developmental, functional, and behavioral effects of injuries in infants and preschool children have not been clearly studied or described in the literature. The major goal of this project is to examine the injury recovery of children and families over a six-month period after hospital discharge. Contributing clinical sites are the Kiwanis Pediatric Trauma Institute at Floating Hospital for Infants and Children, Boston, MA and Baystate Medical Center, Springfield, MA. Physical and functional outcome measures include the Pediatric Evaluation of Disability Index, the Battelle Developmental Scales, and the Rand Child Health Questionnaire to examine health, activity level, and functional status. In addition to the physical and functional measures, child behavior and the psychosocial impact on the family are examined. Recruitment and data collection will continue in Year 4, with an increase in subjects expected following the addition of a second site (Baystate Medical Center). Results of this project will include: 1) the description and frequency of developmental, functional, and health outcomes after injury, 2) the description of child behaviors and the psychosocial impact on families, and 3) description of the differential profiles of injury problems across levels of injury severity, mechanisms, and types of injury, and subsequent patterns of recovery.

TITLE: Intravenous Antibiotic Therapy in Cystic Fibrosis: Home Versus Hospital

PRINCIPAL INVESTIGATOR:
William W. Waring, M.D.
Tulane University School of Medicine
1430 Tulane Avenue
New Orleans, LA 70112

PHONE NUMBER: (504) 588–5601

PROJECT PERIOD: 05/01/87 – 10/31/90

SUMMARY:

The purpose of this study is to compare two treatment locations—hospital and hospital/home—for use of intravenous antibiotics on patients who have cystic fibrosis and who experience acute pulmonary exacerbations. The study compares the safety, efficacy, cost, and psychosocial effects of the two places of treatment.

TITLE:	Model Family-Professional Partnership Interventions
PRINCIPAL INVESTIGATOR:	Betty Pieper, R.N., B.S. New York State Head Injury Association 855 Central Avenue Albany, NY 12206
PHONE NUMBER:	(518) 459–7911
PROJECT PERIOD:	10/01/89 – 09/30/90

SUMMARY:

"Model Family-Professional Partnership Interventions for Childhood Traumatic Brain Injury Survivors," has been awarded funding by NIDRR for three years, October 1, 1988 to September 30, 1991. The following tasks have been completed to date:

a) reanalysis of existing survey findings for application to the present project;

b) evaluation of various instruments in preparation for the design of a caregiver questionnaire which assesses family stressors, coping and functioning in families with a childhood TBI survivor; the questionnaire was mailed in February 1990, and had a 60% response rate;

c) analysis of data from the questionnaire survey; preliminary data has been shared by Dr. Wayne Gordon of Mt. Sinai with the NYSHIA Pediatric Advisory Council on October 9, 1990;

d) review of the literature on interventions which rely on family-professional partnerships in developmental disabilities;

e) documentation of family perceptions of stressors and coping strategies after traumatic brain injury through a Nominal Process Group involving eleven selected families held in October 1989.

Tasks in process:

a) evaluation of the results of the Nominal Group Process by Dr. George Singer of the Oregon Research Institute; the results will be studied by selected professionals who are experts in the TBI service sector and these professionals will meet together in a Consensus Group on November 9, 1990 in order to establish priority interventions;

b) presentation of survey research results (quantitative component) by Wayne Gordon, Ph.D. will be presented on November 9, 1990 to the Consensus Group;

c) development of training materials and dissemination of findings.

TITLE: Modification of the Rehabilitation Workstation for the Clinical Assessment and Training of Upper Extremity Control and Balance

PRINCIPAL INVESTIGATOR: Stephen Haley, Ph.D.
Department of Rehabilitation Medicine
Tufts University School of Medicine
New England Medical Center
750 Washington Street, #75K-R
Boston, MA 02111

PHONE NUMBER: (617) 956–5031

PROJECT PERIOD: 09/30/89 – 09/29/90

SUMMARY:

Individuals with neurological disorders frequently exhibit motor performance deficits in the control of reaching and in maintaining upright balance. It is notable that no clinically feasible and inexpensive quantitative assessment tools are currently available to examine deficits in reaching and balance. This project will modify existing technology developed for a microcomputer workstation to make it applicable for the clinical assessment of upper extremity control and balance. Through hardware and software modifications and the refinement of assessment tasks, motor performance data on reaching and balance will be acquired, reduced, and analyzed. Response times and postural stability data will be collected during standing and sitting balance tasks. The uniqueness of the system lies in the fact that reaching and postural stability performance data will be collected simultaneously. Clinical feasibility testing on a group of patients with neurological impairments and on a matched control group will examine variability due to repeated testings and the sensitivity of the tests to detect motor performance deficits. The project will also explore the use of the system as a treatment strategy, taking advantage of its capabilities to provide immediate feedback of performance.

At the conclusion of this project, a clinically feasible, inexpensive, and quantitative method of measuring upper extremity control and balance will be available. Through the development of test manuals and technical documentation, training packages for professionals, and the availability of software and inexpensive hardware, wide dissemination and utilization of the modified Rehabilitation Workstation for the clinical assessment and training of reaching and balance will be achieved.

TITLE:	National Clearinghouse on Family Support and Children's Mental Health
PRINCIPAL INVESTIGATOR:	Marilyn McManus, J.D., M.S.W. Regional Research Institute for Human Services Portland State University P.O. Box 751 Portland, OR 97207–0751
PHONE NUMBER:	(503) 725–4040
PROJECT PERIOD:	10/01/89 – 09/30/94

SUMMARY:

The National Clearinghouse on Family Support and Children's Mental Health is the first clearinghouse designed to serve families of children with serious emotional disorders as well as professionals, policy-makers and other interested persons. It includes a national toll-free telephone service (800–628-1696), a computerized data bank, a series of fact sheets on issues pertaining to children who have emotional disabilities and their families, a state-by-state resource file, and the addition of a family resource coordinator to the Center's staff.

Available fact sheets address the following topics: children's mental, emotional, and behavioral disabilities; resources (books, journals, newsletters, and films) addressing children's mental health issues; starting parent/family support groups; financing; early intervention services; and descriptions of specific children's emotional disabilities including childhood depression, attention deficit hyperactivity disorder, and childhood schizophrenia.

TITLE: Nutrition Project for Children with Special Needs

PRINCIPAL INVESTIGATOR: Daniel J. Gossert, A.C.S.W., M.P.H.
Colorado Department of Health
Family and Community Health Services
4210 East 11th Avenue
Denver, CO 80220

PHONE NUMBER: (303) 331–8359

PROJECT PERIOD: 10/01/88 – 09/30/91

SUMMARY:

An estimated 73 percent of the children in the Colorado Handicapped Children's Program have nutritional problems which may interfere with optimal growth and development and may increase the debilitating effects of their handicap or chronic illness. Prior to the implementation of the Nutrition Project for Children with Special Needs, there was no systematic way to find and offer nutrition intervention to children in the Colorado Handicapped Children's Program. The goal of the Nutrition Project for Children with Special Needs is to develop a replicable nutrition intervention system to reduce or prevent the debilitating effects of poor nutrition in children with handicapping conditions and chronic illness.

TITLE:	Pediatric Pulmonary Center (Gainesville, FL)
PRINCIPAL INVESTIGATOR:	Arlene A. Stecenko, M.D. University of Florida J. Hillis Miller Health Center Box J-296 Gainesville, FL 32610
PHONE NUMBER:	(904) 392–4458
PROJECT PERIOD:	07/01/85 – 06/30/90

SUMMARY:

The purpose of this project is to provide exemplary health care for a segment of the large and increasing number of children with chronic and acute respiratory disease and to provide interdisciplinary training to alleviate the shortage of health professionals required to meet the needs of this patient population. Educational programs include interdisciplinary inpatient and outpatient management experiences, didactic curriculums, and a variety of other activities tailored to the students' interests and goals. Center faculty provide services in the form of consultative clinics and continuing education programs. Both faculty and students are active in research, patient and community education, and development of tools for patient management.

TITLE: Physical Functioning and Motor Outcomes of Injured Children and Adolescents

PRINCIPAL INVESTIGATOR: Stephen Haley, Ph.D.
Department of Rehabilitation Medicine
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New England Medical Center
750 Washington Street
#75K–R
Boston, MA 02111

PHONE NUMBER: (617) 956–5031

PROJECT PERIOD: 01/01/88 – 12/31/92

SUMMARY:

Children with traumatic injuries frequently exhibit residual physical and functional motor deficits. The major goal of this project is to examine the physical functioning and motor recovery of children and adolescents after a traumatic injury. Contributing clinical sites are the Kiwanis Pediatric Trauma Institute at Floating Hospital for Infants and Children, Boston, MA and Baystate Medical Center, Springfield, MA. Physical and functional motor outcomes are being examined at hospital discharge, one month, three months, and six months after hospital discharge. Pre-injury data (retrospective from parents) includes the social competence and activity scale of the Child Behavior Checklists and the physical health section of the Rand Child Health Scale. Measurements taken at hospital discharge are the short form of the Scales of Independent Behavior and the Fine Motor Section of the Bruininks-Oseretsky Test of Motor Proficiency. General measures of physical function and activity taken at one, three, and six months are the physical scales of the Child Health Scale. More specific and detailed measures taken at one and six months post-discharge on those children who are able to return for a follow-up visit are the Scales of Independent Behavior, the gross and fine motor sections of the Bruininks-Oseretsky Test of Motor Proficiency, and the social competence and activity scales of the Child Behavior Checklist. Outcomes will include: 1) the description and frequency of motor and functional outcomes after injury, and 2) the differential pattern of injury related problems across severity levels of trauma.

TITLE: Primary Care Physicians: Caring for Low-Income Children with Special Health Needs

PRINCIPAL INVESTIGATOR: Charles P. LaVallee
Western Pennsylvania Caring Foundation, Inc.
Fifth Avenue Place, Suite 3012
Pittsburgh, PA 15222

PHONE NUMBER: (412) 255–8127

PROJECT PERIOD: 10/01/89 – 09/30/94

SUMMARY:

In this program, project staff will work with the Pennsylvania Department of Health to establish a model for a statewide program designed to provide coordinated, family-centered, community-based care for chronically ill children. The project aims to provide physicians with the resources necessary to guide the care of a chronically ill child and to give families of chronically ill children the information and support they need to interact effectively with all caregivers. Program activities will include conducting a prevalence survey to determine the parameters of the target population with respect to chronic illness and disability; performing an assessment of primary care physician in western Pennsylvania with respect to educational needs, awareness of services, and level of knowledge; and providing a continuing medical education program.

TITLE: Psychosocial and Family Outcomes of Injured Children and Adolescents

PRINCIPAL INVESTIGATOR: Donald Wertlieb, Ph.D.
Department of Rehabilitation Medicine
Tufts University School of Medicine
New England Medical Center
750 Washington St
#75K–R
Boston, MA 02111

PHONE NUMBER: (617) 956–5031

PROJECT PERIOD: 01/01/88 – 12/31/92

SUMMARY:

Rehabilitation services for childhood trauma include a broad array of child and family interventions to enhance the recovery process. Rehabilitation programs are not complete, nor are they likely to be effective if the negative psychosocial impact of injury on children and families is not adequately addressed. The major goal of this project is to understand the nature and extent of child and family psychosocial problems after traumatic injury. Contributing clinical sites are the Kiwanis Pediatric Trauma Institute at Floating Hospital for Infants and Children, Boston, MA. A battery of measures assess child and family psychosocial status as well as school reintegration status at one month and again at six month post discharge. The measures include the Child Behavior Checklist, the Impact of Family Scale and School Reintegration Checklist. At the six-month follow-up, an additional measure is introduced with a Teacher Questionnaire to assess school behavior and academic performance. Outcomes of this project will include: 1) the description and frequency of child behavior problems, family disruption and stress, and school reintegration problems after injury, 2) the differential pattern of injury related psychosocial and school problems across varying trauma severity levels, and 3) the extent of recovery of behavior, psychosocial and school problems for injured children over a six-month periods, and how psychosocial factors relate to injury recovery.

TITLE: Reasonable Efforts in Permanency Planning

PRINCIPAL INVESTIGATOR: Christopher Petr, Ph.D.
Beach Center on Families and Disability
3111 Haworth
The University of Kansas
Lawrence, KS 66045

PHONE NUMBER: (913) 864–7600

PROJECT PERIOD: 07/01/90 – 06/30/91

SUMMARY:

Children with disabilities often seem to be high risks for out-of-home placement. This project will develop a state-of-the-art definition of “reasonable efforts” to maintain children with emotional disorders (ED), developmental disabilities (DD), and technology support (TS) in permanent placements in the least restrictive environment. The overall research question is: What state policies, programs, supports, and values regarding “reasonable efforts” are the most conducive to maintaining those children with emotional disorders, developmental disabilities, and technology support in the least restrictive, most home-like environments?

To answer this question, we will investigate two aspects of this issue during the first two years of the project. The first involves a policy analysis of one exemplary state’s current “reasonable efforts.” The second centers on understanding the stresses faced by families and the match between their needs and the same state’s “reasonable efforts.”

This project has:

- Begun data collection and analysis.

This project will:

- Complete data collection and analysis;
- Initiate educational and other change efforts to achieve implementation of the state-of-the-art definition of “reasonable efforts” in one or two targeted states;
- Work with family organizations, service providers, and policy makers;
- Submit the policy analysis for publication in a peer-reviewed journal;
- Prepare a manual on change efforts for family organizations;
- Present the content of the manual at annual meetings of family and provider organizations.

TITLE: Regional Program to Improve the Health Status of Children with Rheumatic Diseases

PRINCIPAL INVESTIGATOR: Jane G. Schaller, M.D.
New England Medical Center
Department of Pediatrics, Coordinating Center
750 Washington Street, Box 286
Boston, MA 02111

PHONE NUMBER: (617) 956–5071

PROJECT PERIOD: 07/01/87 – 06/30/90

SUMMARY:

This project seeks to improve the health status of children with rheumatic diseases in New England as measured by reductions in the number of days lost from school by these children. Activities include development of discipline-specific standards of care; education of local school systems, parents, and tertiary center teams; outreach to underserved areas; and development of community-based programs for families, including parent support groups and telephone networks.

TITLE: Rehabilitative and Developmental Care of the Very Low Birthweight (VLBW) Newborn: Testing a Clinical Model

PRINCIPAL INVESTIGATOR: Heidelise Als, Ph.D.
Enders Pediatric Research Laboratories
M–29, Children's Hospital
320 Longwood Avenue
Boston, MA 02115

PHONE NUMBER: (617) 956–5031

PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

The newborn with a birth weight of <1250g (<2$^{1}/_{2}$ lbs.) who requires mechanical ventilation is at very high risk for intraventricular hemorrhage (IVH) and for chronic lung disease (BPD), two potentially severely handicapping conditions jeopardizing survival and normal development. We hypothesize that caregiving in the Newborn Intensive Care Nursery (NICU), which is from day one on, consistently geared not only to the medical needs, but also to the individual newborn's developmental/behavioral needs and those of the infant's family reduces the initial danger of intraventricular bleeding, decreases respirator dependency, and improves significantly the developmental outcome.

We have successfully tested this hypothesis in a research model by utilizing an innovative developmental approach to individualized caregiving with a randomly selected experimental group and comparing outcome to a control group. We have used a structured detailed observation and written feedback procedure every 10th day, performed by trained developmental specialists in conjunction with developmental observational training of a group of primary bedside caregiving nurses. Outcome of the experimental group showed shorter stay on the ventilator, in supplemental oxygen, and on gavage feedings, lower incidence of intraventricular hemorrhage, reduced severity of bronchopulmonary dysplasia as well as much improved developmental outcome of the child and of the family. The second phase of the study has been to test a clinically integrated model of implementation by testing maintenance of quality control of the consistency of implementation of individualized care delivered by specially trained primary nursing teams through ongoing feedback and support by the developmentally trained clinical nurse specialist (CNS) in the NICU> Twenty VLBW respirator-dependent infants meeting the study criteria were randomly assigned in the course of a 22-month intake period to trained nursing teams supported by the developmental CNS. The outcome of these infants and their families is compared to 20 control infants' outcomes. Current analysis of the data will show whether their outcome is improved, as was the case in phase I of the research. Should this be so, we will have the basis of a cost-effect model which can be instituted and transmitted to other institutions via the training program we have developed.

TITLE: RTC in Rehabilitation and Childhood Trauma Project: National Pediatric Trauma Registry

PRINCIPAL INVESTIGATOR:
Carla Di Scala, Ph.D.
Department of Rehabilitation Medicine
Tufts University School of Medicine
New England Medical Center
750 Washington St
#75K–R
Boston, MA 02111

PHONE NUMBER: (617) 956–5031

PROJECT PERIOD: 01/01/88 – 12/31/92

SUMMARY:

The National Pediatric Trauma Registry (NPTR) is a collection of information about unintentional injuries occurring in children and young adults admitted to trauma centers for treatment. Started in April 1985, it currently includes about 22,000 cases of injuries and is increasing at a rate of approximately 6,000 cases a year.

The Registry is supported by the American Pediatric Surgical Association (APSAP) and data to the Registry are contributed by 50 trauma centers of children's hospitals on a voluntary basis.

The data collected in the Registry includes demographics, detailed description of the injury event, management of the victim at the scene, severity at the time of admission to the trauma center, management at the trauma center, discharge status, functional assessment at discharge, diagnoses and procedures performed.

Measures of severity include Abbreviated Injury Scale (AIS), Injury Severity Score (ISS), Glasgow Coma Scale (GCS), and Pediatric Trauma Score (PTS). Functions at discharge are assessed by a checklist of daily activities as well as by the Functional Independence Measure (FIM), where applicable. Diagnosis and procedure are recorded using the ICD-9 CM codes. The external causes of injury and accident scene are recorded using E-codes.

The Registry encompasses many aspects of pediatric trauma. It has been used to document pediatric injury outcome and to assess acute and rehabilitative treatment efficacy. Work is currently in progress to quantify morbidity resulting from injuries and to identify predictions of long-term outcomes.

TITLE: Siblings of Children with Disabilities

PRINCIPAL INVESTIGATOR:
Barbara Leonard, Ph.D.
Center for Children with Chronic Illness and Disability
Box 721 UMHC
Minneapolis, MN 55455

PHONE NUMBER: (612) 626–4032

PROJECT PERIOD: 1991 – 1994

SUMMARY:

Siblings will be studied concurrently to determine their psychosocial adjustment to living in a family with a chronically ill child. All siblings between the ages of 6 months and 21 years will be followed using the same measurement tools as those in the Longitudinal Study. Interviews with parents and siblings will be included. Our past research with siblings of medically fragile children and children with diabetes, epilepsy, cancer, and cystic fibrosis indicate a 3–5 fold increase in behavior problems over a normal population of children. The present study will provide a unique opportunity to examine family factors as well as those specific to children (age, sex, birth order) which contribute to their adjustment over time. Because no longitudinal data on siblings or chronically ill children is currently available, the findings from this study could be a significant contribution to the fields of family social science and child development.

TITLE: Survey of Chronically Ill Children's Use of Time Out of School

PRINCIPAL INVESTIGATOR:
Bonnie Holaday, R.N., D.N.S.
University of California at San Francisco
Family Health Care Nursing
San Francisco, CA 94143

PHONE NUMBER: (415) 476–4663

PROJECT PERIOD: 04/01/87 – 03/31/90

SUMMARY:

The primary aim of this study is to describe and analyze the everyday out-of-school life experiences of chronically ill school-age children, and to examine the effects of different ecological contexts on the child's out-of-school life. Based on the analysis of data from a pilot study, two general hypotheses have been developed: (1) The patterns of chronically ill children's time use depend on the extent to and the manner in which parents and others engage in joint activities with them; and (2) the capacity of the parents to engage in such joint behavior depends on the extent to which there exist external support systems that provide opportunity, assistance, resources, and channels of communication.

TITLE:	Survey of Health Care Utilization and Family Out-of-Pockets Expenses
PRINCIPAL INVESTIGATORS:	Paul Newacheck, M.P.P. Peggy McManus, M.H.S. Center for Children with Chronic Illness and Illness Box 721 UMHC Minneapolis, MN 55455
PHONE NUMBER:	(612) 626–4032
PROJECT PERIOD:	1991 – 1994

SUMMARY:

This component of the longitudinal study is designed to provide new information on the costs incurred by families in caring for a chronically ill child. Through a mail-out survey of over 500 families conducted at regular intervals, the project will collect information on direct costs such as out-of-pocket expenses for hospital care, and indirect costs such as the value of lost parental employment opportunities. In addition, information will be collected on utilization of a range of health services by chronically ill children. These data will permit us to draw a relatively complete profile of the utilization and expenditure patterns for a fairly large sample of chronically ill children.

The project will also collect information on health insurance coverage. This information will be used to assess how health insurance influences use of services and family out-of-pocket expenses. Included also will be survey questions concerning perceptions of financial and insurance barriers to receiving needed health care services designed to elicit degree of worry or concern about health care bills. The goal of the project is to establish a database that can be used to address several key public policy issues, including:

Health Care Utilization Patterns

1. What services do chronically ill children use?
2. How does service use vary by age, severity, and diagnosis?
3. How do utilization patterns of chronically ill children compare to those of children without chronic conditions?

Direct Costs of Caring for Chronically Ill Children

1. What is the range of family out-of-pocket expenses for caring for a chronically ill child?
2. How do these expenditures vary by age, severity, and diagnosis?
3. How many families experience out-of-pocket expenses in excess of 5, 10, or 15 percent of their family income over the course of the year?
4. Which types of health care services lead to high out-of-pocket expenses?

TITLE: The National Adolescent and Child Treatment Study (NACTS)

PRINCIPAL INVESTIGATORS:
Paul Greenbaum, Ph.D.
Starr Silver, Ph.D.
Research and Training Center for Children's Mental Health
University of South Florida
Florida Mental Health Institute
13301 Bruce B. Downs Boulevard
Tampa, FL 33612

PHONE NUMBER: (813) 974–4500

PROJECT PERIOD: 09/28/89 – 09/27/94

SUMMARY:

The purpose of this observational study is to describe the characteristics, functional levels, receipt of services, and outcomes among a large (N = 812) sample of children and adolescents with serious emotional problems. This project is a seven-year longitudinal study that was initiated by the Center in 1984. The sample is comprised of children who, at the time of initial data collection, resided in six states. Within each state, approximately half of the sample was obtained from children served in special education programs, and half from residential mental health facilities. Three age cohorts are being studied: pre-adolescents (ages 8 to 11), adolescents (ages 12 to 14), and older adolescents (ages 15 to 18). The National Adolescent and Child Treatment Study (NACTS) is collecting data from the youngsters and their parents and is providing important epidemiological and systems knowledge on such issues as the duration of childhood psychopathology, the services received by this sample (including those received as children progress to early adulthood), the long-term outcomes among the youngsters, and key predictors of these outcomes.

TITLE: University Affiliated Interdisciplinary Training Facility (Miami)

PRINCIPAL INVESTIGATOR:
Robert S. Stempfel, M.D.
Mailman Center for Child Development
University of Miami School of Medicine
P.O. Box 016820
Miami, FL 33101

PHONE NUMBER: (305) 547–6635

PROJECT PERIOD: 07/01/89 – 06/30/94

SUMMARY:

The Mailman Center for Child Development is a University Affiliated Program. The primary purpose of the program is to increase the quality and number of professionals in the field of maternal and child health and to prepare them to accept leadership roles in the community. The Mailman Center is a teaching, research, and service institute dedicated to the prevention of handicapping conditions, the prevention of secondary consequences of existing handicaps, and the provision of family-centered, community-integrated services for persons with handicapping conditions and other special health care needs.

Screening Projects

TITLE: Alabama Newborn Hemoglobinopathy Screening Project

PRINCIPAL INVESTIGATOR: Doris M. Barnette, A.C.S.W.
Alabama Department of Public Health
Bureau of Family Health Services
434 Monroe Street
Montgomery, AL 36130-1701

PHONE NUMBER: (205) 261–5052

PROJECT PERIOD: 10/01/88 – 09/30/90

SUMMARY:

This project seeks to expand Alabama's present newborn screening program. The project objectives are to ensure that: (1) Every newborn will be screened, (2) families of children with hemoglobinopathies will receive medical treatment and social support, and (3) health care providers statewide will receive adequate training regarding the identification and management of sickle cell disease and other hemoglobinopathies.

TITLE: Arkansas Newborn Sickle Cell Screening Program

PRINCIPAL INVESTIGATOR: Deborah Bryant, M.D.
Arkansas Department of Health
Bureau of Public Health Programs
4815 West Markham Street
Little Rock, AR 72205-3687

PHONE NUMBER: (501) 661–2528

PROJECT PERIOD: 10/01/88 – 09/30/90

SUMMARY:

This project seeks to provide hemoglobinopathy screening to all newborns in Arkansas. Under a collaborative program involving several agencies and foundations, the primary physicians and the parents of all newborns who have a significant hemoglobinopathy or are carriers will be notified; infants will be referred for medical evaluation, treatment, followup, and genetic counseling. Inservice programs will be provided to physicians in staff meetings at key hospitals.

TITLE: Automated System for Monitoring Treatment Services for Children with Metabolic and Endocrine Disorders

PRINCIPAL INVESTIGATOR: Darryl Leong, M.D., M.P.H.
Vermont Department of Health
Medical Services Division
P.O. Box 70
1193 North Avenue
Burlington, VT 05402

PHONE NUMBER: (802) 863-7347

PROJECT PERIOD: 10/01/89 – 09/30/90

SUMMARY:

The Vermont Newborn Screening Program has no organized system of followup to ensure that children with disorders diagnosed by screening are enrolled in treatment services or to monitor the quality of those services. The goal of this project is to have a system in place to ensure that the families of all children identified by the newborn screening program as having a disorder will have appropriate information and other sources available and will have those services monitored in an appropriate manner.

TITLE: Biochemical Genetic Laboratory

PRINCIPAL INVESTIGATOR: Edwin Naylor, Ph.D.
Western Pennsylvania Hospital
4800 Friendship Avenue
Pittsburgh, PA 15224

PHONE NUMBER: (412) 578-7348

PROJECT PERIOD: 07/01/86 – 06/30/93

SUMMARY:

The purpose of this project is to establish a national screening and confirmation center for the diagnosis of rare cofactor variant forms of phenylketonuria (PKU). This center will provide routine screening of all newborns diagnosed as having either classical PKU or mild hyperphenylalaninemia (HPA). The training of postdoctoral fellows as well as the education of physicians, medical and graduate students, and the public on the nature of PKU cofactor defects are also project objectives.

TITLE: Colorado Regional Newborn Screening Program

PRINCIPAL INVESTIGATOR: Robert S. McCurdy, M.D., M.P.H.
Colorado Department of Health
Family Community Health Division
4210 East 11th Avenue
Denver, CO 80220

PHONE NUMBER: (303) 331–8373

PROJECT PERIOD: 10/01/89 – 09/30/90

SUMMARY:

The goals of the Colorado Regional Newborn Screening Program are to: (1) Improve the efficiency of the existing Regional Newborn Screening Program in Arizona, Colorado, and Wyoming by improving the automation of its data system; (2) collect information and data germane to the effectiveness and impact of newborn screening and counseling for sickle cell trait; and (3) assess how well informed physicians are about newborn screening for cystic fibrosis (CF), evaluate information physicians have about CF in infancy, ascertain the type of information physicians provide to families concerning CF screening, determine the extent of physician awareness and concern regarding parental emotional responses to CF screening, and understand whatever reservations physicians may have regarding the screening process or the screening itself.

TITLE: Counseling and Education for Families of Newborns Identified with Hemoglobinopathies

PRINCIPAL INVESTIGATOR: Jennifer Carnes, R.N.
Florida Department of Health and
Rehabilitative Services
Children's Medical Services
1311 Winewood Boulevard
Building 5, Room 118
Tallahassee, FL 32399–0700

PHONE NUMBER: (904) 488–1459

PROJECT PERIOD: 10/01/87 – 09/03/90

SUMMARY:

The goal of this project is to develop and implement a comprehensive education program for physicians, nurses, counselors, social workers, health educators, and other health care providers which will enable them to provide information to those identified as having sickle cell trait by the statewide newborn screening program. Community outreach and educational activities will also be conducted.

TITLE: Development and Implementation of a Comprehensive Newborn Screening Program for Sickle Cell Diseases

PRINCIPAL INVESTIGATOR: Alice S. Linyear, M.D., M.P.H.
Virginia Department of Health
Division of Maternal and Child Health
109 Governor Street
Richmond, VA 23219

PHONE NUMBER: (804) 786-7367

PROJECT PERIOD: 10/01/87 - 09/30/90

SUMMARY:

The goal of this project is to reduce morbidity and mortality from sickle cell diseases in infants and young children in Virginia. Project objectives are to: (1) Expand an existing, limited pilot newborn screening program; (2) conduct transition activities to add the pilot screening program to the current newborn metabolic screening tests; and (3) introduce the screening program to the professional community and public though extensive education.

TITLE: Development of Statewide Screening for Hemoglobinopathies in Pennsylvania

PRINCIPAL INVESTIGATOR: Daniel L. Brant, M.S.W.
Pennsylvania Department of Health
Division of Maternal and Child Health
P.O. Box 90
Harrisburg, PA 17108

PHONE NUMBER: (717) 787-7440

PROJECT PERIOD: 10/01/89 - 09/30/90

SUMMARY:

The goal of this project is to conduct a pilot newborn screening program for sickle cell disease and other abnormal hemoglobins in Philadelphia County during the project period, in preparation for the implementation of statewide hemoglobinopathy screening by October 1, 1990.

TITLE: Follow-up of Identified Newborns with Hemoglobinopathies

PRINCIPAL INVESTIGATOR: Virginia Herlong
South Carolina Department of Health and Environmental Control
Division of Children's Health
Newborn Screening Program
2600 Bull Street
Columbia, SC 29201

PHONE NUMBER: (803) 737-4050

PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

This project has two main goals. The first is to decrease infant and early childhood morbidity and mortality among children with sickle cell disease by implementing a case management system, initiating prophylactic antibiotics before infants reach 4 months of age, arranging for specialty medical services, and assuring that these infants have a primary care source. The second goal is to identify, counsel, and make referrals for couples at risk for having a child with sickle cell disease.

TITLE: Hemoglobinopathy Screening in California

PRINCIPAL INVESTIGATOR: George C. Cunningham
California Public Health Foundation
2001 Addison Street, Suite 210
Berkeley, CA 94704-1103

PHONE NUMBER: (415) 644-8200

PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

This project proposes to add a program of hemoglobinopathy screening, education, followup, and counseling to the existing statewide newborn screening program. It will supplement available resources and will provide the following specific elements needed for comprehensive screening: Education of health care providers and the public; implementation of screening policies and procedures regarding thalassemias and other hemoglobinopathies; and development of a hemoglobinopathy registry to support long-term followup and counseling.

TITLE: Illinois Project for Statewide Screening and Follow-up of Newborns for Hemoglobinopathies

PRINCIPAL INVESTIGATOR:
Stephen Saunders, M.D.
Illinois Department of Public Health
535 West Jefferson
Springfield, IL 62761

PHONE NUMBER: (217) 782-2736

PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

The goal of this project is to enable clients with hemoglobinopathies and their families to improve their quality of life. Specifically, the project expands the current infant screening program to include screening for hemoglobinopathies, facilitate followup services, provide parents of affected children with counseling, and increase health care provider knowledge regarding hemoglobinopathies.

TITLE: Implementation of Universal Newborn Screening for Hemoglobinopathies and Congenital Adrenal Hyperplasia of Newborns in Massachusetts

PRINCIPAL INVESTIGATOR:
Marvin L. Mitchell, M.D.
Massachusetts Health Research
Institute, Inc.
101 Tremont Street
Boston, MA 02108

PHONE NUMBER: (617) 426-6378

PROJECT PERIOD: 10/01/89 – 09/30/90

SUMMARY:

This project seeks to implement universal screening of newborns for sickle cell disease and congenital adrenal hyperplasia in Massachusetts; establish with the Boston Sickle Cell Center, a referral network for treatment and counseling of children with sickle cell disease and their families; establish a reporting and followup system to ensure that all newborns with sickle cell disease receive appropriate treatment and families receive counseling; implement a fee-based system that will support screening, treatment, and counseling; and establish a followup system for treatment of congenital adrenal hyperplasia.

TITLE: Improved Newborn Screening for Congenital Adrenal Hyperplasia

PRINCIPAL INVESTIGATOR: Lindsay Fiske Hoffman
North Carolina State Laboratory of Public Health
Department of Human Resources
306 North Wilmington Street
P.O. Box 28047
Raleigh, NC 27611

PHONE NUMBER: (919) 733–3937

PROJECT PERIOD: 10/01/89 – 09/30/90

SUMMARY:

This project will add a confirmatory test to newborn screening for congenital adrenal hyperplasia (CAH) that should reduce the false positive rate to very low levels. The goal of this project is to design a screening program for CAH that will work in North Carolina and to accumulate enough data for a statistically significant determination of prevalence in the State. The project will provide information for the State to use in considering the need for and cost-benefit ratio of adding CAH screening to the North Carolina program. Results of this study will also be valuable to other Southeastern States in making their decision about CAH screening.

TITLE: Improved Newborn Screening for Hemoglobinopathies

PRINCIPAL INVESTIGATOR: Christine Papadea, Ph.D.
Georgia Department of Human Resources
Division of Public Health
Laboratory Unit, Room 13-H
47 Trinity Avenue, S.W.
Atlanta, GA 30334

PHONE NUMBER: (404) 656–4850

PROJECT PERIOD: 10/01/89 – 09/30/90

SUMMARY:

Georgia's newborn screening program for hemoglobinopathies is presently targeted at infants of designated ethnic/racial groups considered to be at high risk for sickle cell anemia and related hemoglobinopathies. Initial data suggest that only about 80 percent of the target population is being tested and reported to the State. This retrieval failure is due, in part, to the fact that two types of neonatal blood specimens—liquid cord for hemoglobins and heel-prick on filter paper for metabolic disorders—must be collected. For various reasons, cord blood samples are not always obtained. This study will determine whether filter paper blood spots collected in the statewide newborn screening program for metabolic disorders can be used in an isoelectric focusing technique to screen for abnormal hemoglobins.

TITLE: Information System to Enhance Newborn Screening Services in Tennessee and Mississippi

PRINCIPAL INVESTIGATOR: Mary Jane Sassaman, M.A., M.T.A.S.C.P.
Tennessee Department of Health and Environment
Bureau of Health Services Administration
100 Ninth Avenue, North
Nashville, TN 37219

PHONE NUMBER: (615) 741–7335

PROJECT PERIOD: 10/01/89 – 09/30/90

SUMMARY:

A comprehensive newborn screening information system is needed to effectively and efficiently monitor the status of all specimens throughout the screening process to minimize the risk that infants with one of these disorders might fall through the cracks. The project goals are to: (1) Ensure that infants are not lost to followup prior to completion of the newborn screening process; (2) improve the efficiency of specimen processing in the State laboratory; and (3) enhance quality assurance measures for the newborn screening program.

TITLE: Initiation of Hemoglobinopathy Screening in Utah

PRINCIPAL INVESTIGATORS: Thomas J. Wells, M.D., M.P.H.
Susan L. Mottice, Ph.D.
Utah Department of Health
44 Medical Drive
Salt Lake City, UT 84113

PHONE NUMBER: (801) 584–8237 or 584–8300

PROJECT PERIOD: 10/01/89 – 09/30/90

SUMMARY:

In this project, all infants born during the study period will be screened for hemoglobinopathies using isoelectric focusing. Infants with abnormal hemoglobin will be identified and their families given appropriate counseling. A coordinated system of community resources will be established for followup of affected infants. The prevalence of hemoglobin carriers and disease will be determined. Data obtained from this study will be used to justify expansion of the current newborn screening program.

TITLE: Iowa Sickle Cell and Other Major Hemoglobinopathies Screening and Follow-up Program: Patient Tracking and Monitoring

PRINCIPAL INVESTIGATORS:
Pedro A. de Alarcon, M.D.
Richard P. Nelson, M.D.
University of Iowa Hospitals and Clinics
Department of Pediatrics
Division of Pediatric Hematology
Iowa City, IA 52242

PHONE NUMBER: (319) 356–4830

PROJECT PERIOD: 10/01/88 – 09/30/90

SUMMARY:

This project supports the patient tracking and monitoring component of the Iowa Hemoglobinopathy Program. The four main objectives are to (1) develop a computer-based data management system for hemoglobinopathy screening; (2) ensure the transfer of data from the screening program to the statewide comprehensive care centers and to the regional genetic consultation service and Child Health Specialty Clinics; (3) facilitate communication between program staff and community health professionals; and (4) disseminate the data management system to other States.

TITLE: Louisiana Neonatal Sickle Cell Screening and Follow-up Project

PRINCIPAL INVESTIGATOR:
Charles Myers
Louisiana Department of Health and Hospitals
Office of Public Health
Genetic Diseases Program
P.O. Box 60630
New Orleans, LA 70160

PHONE NUMBER: (504) 568–5070

PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

To reduce morbidity and morality of infants with sickle cell disease, this project will establish a statewide system which provides both early identification of neonates with the disease and referrals to comprehensive followup services. A sickle cell task force will link agencies in order to improve care for persons with sickle cell disease. Education on sickle cell disease and trait will be provided to health care providers and to parents of affected children.

TITLE: Michigan Newborn Screening: A Proposal to Improve Efficiency and Quality of Testing and Follow-up Services

PRINCIPAL INVESTIGATOR: Robert Martin, Dr.P.H.
Michigan Department of Public Health
3500 North Logan Street
Lansing, MI 48909

PHONE NUMBER: (513) 335–8067

PROJECT PERIOD: 10/01/89 – 09/30/90

SUMMARY:

This project seeks to increase the efficiency of followup for sickle cell disease and sickle-hemoglobin C disease so that with over 90 percent of presumptive positive hemoglobin tests the suspected infant is retested and given medical treatment if the diagnosis is established. In addition, the project proposes to increase the efficiency of followup for metabolic diseases (PKU, MSUD, galactosemia, and biotinidase deficiency) from 90 to 95 percent, and hypothyroidism followup from 92 to 95 percent or greater.

TITLE: Mississippi Hemoglobinopathy Screening, Diagnosis, and Treatment Project

PRINCIPAL INVESTIGATOR: Daniel R. Bender
Mississippi State Department of Health
Genetic Screening Program
P.O. Box 1700
Jackson, MS 39215-1700

PHONE NUMBER: (601) 960–7619

PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

The purpose of this project is to reduce morbidity and mortality due to sickle cell disease and other hemoglobinopathies in Mississippi. Project objectives are to: (1) Establish a statewide program of newborn screening for hemoglobinopathies; (2) provide education and counseling to patients and families identified through the screening program; and (3) demonstrate that the system to be implemented effects significant reductions in unnecessary repeat screenings for hemoglobinopathies.

TITLE: Missouri Hemoglobinopathies Newborn Screening Project

PRINCIPAL INVESTIGATOR: N. Aurita Prince
Missouri Department of Health
1730 East Elm
P.O. Box 570
Jefferson City, MO 64102

PHONE NUMBER: (314) 751–6254

PROJECT PERIOD: 10/01/88 – 09/30/90

SUMMARY:

The goal of this project is to reduce the morbidity and mortality associated with sickle cell disease in the early years of life. To achieve this goal, the project will identify through screening all infants born with hemoglobinopathies; develop resources to provide comprehensive services to these infants; and educate parents, health professionals, and the public about hemoglobinopathies.

TITLE: Neonatal Screening for Sickle Cell Disease and Sickle Cell Trait

PRINCIPAL INVESTIGATOR: Azzie Young, Ph.D.
Kansas Department of Health and Environment
Bureau of Family Health
900 Southwest Jackson Street, 1005 N
Topeka, KS 66612-1290

PHONE NUMBER: (913) 296–1300

PROJECT PERIOD: 10/01/89 – 09/30/90

SUMMARY:

The goal of this project is to initiate a neonatal screening, diagnosis, and treatment program for sickle cell trait and sickle cell disease by January 1, 1990. The objectives of the project are to: (1) Develop the screening capabilities in the Kansas Department of Health and Environment laboratories by December 1, 1989; (2) define the parameters of the sickle cell anemia and sickle cell trait screening, diagnosis, and treatment program; and (3) develop and implement education and public awareness activities.

TITLE: Newborn Screening and Counseling Program

PRINCIPAL INVESTIGATORS:
Roland B. Scott, M.D.
Catherine U. Uzoma, Ph.D., M.P.H.
Howard University
Center for Sickle Cell Disease
2121 Georgia Avenue, N.W.
Washington, DC 20059

PHONE NUMBER: (202) 636–7930

PROJECT PERIOD: 10/01/88 – 09/30/90

SUMMARY:

The purpose of this project is to develop and implement a comprehensive newborn screening program. The program will be designed to: (1) Expand existing services to include education, counseling, and followup testing for families of infants with abnormal hemoglobin trait; (2) assure followup and comprehensive management of infants with clinically significant hemoglobinopathies; and (3) reduce the need for repeated screening in childhood, adolescence, and adulthood.

TITLE: Newborn Screening for Early Diagnosis and Treatment of Children with Hemoglobinopathies in Puerto Rico

PRINCIPAL INVESTIGATOR:
Pedro J. Santiago Borrero, M.D.
University of Puerto Rico Medical School
Medical Science Campus
G.P.O. Box 5067
San Juan, PR 00936

PHONE NUMBER:

PROJECT PERIOD: 10/01/89 – 09/30/90

SUMMARY:

The purpose of this project is to screen newborns for hemoglobinopathies as a means of establishing an early diagnosis; initiating prompt comprehensive care; and reducing morbidity, complications, and mortality among affected children. Procedures will be established to provide information, maintain confidentiality of screening results, and provide appropriate program evaluation.

TITLE: Newborn Screening for Hemoglobinopathies

PRINCIPAL INVESTIGATOR:
Kenneth A. Pass, Ph.D.
New York State Department of Health
Wadsworth Center for Laboratories and Research
Empire State Plaza
Albany, NY 12201-0509

PHONE NUMBER: (518) 473-7552

PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

The goals of this project are to: (1) Establish an expanded followup system within the New York State Newborn Screening Program; (2) establish a mechanism whereby parents of children found to have trait conditions are uniformly notified of this finding; and (3) establish a mechanism whereby adolescents with sickle cell trait are made aware of their carrier state and provided with sensitive, nondirective counseling.

TITLE: Newborn Screening for Sickle Cell Disease

PRINCIPAL INVESTIGATOR:
Patricia K. Nicol, M.D., M.P.H.
Kentucky Department for Health Services
Division of Maternal and Child Health
Cabinet for Human Resources
275 East Main Street
Frankfort, KY 40621

PHONE NUMBER: (502) 564–4830

PROJECT PERIOD: 10/01/88 – 09/30/90

SUMMARY:

The goal of this project is to reduce infant morbidity and mortality due to sickle cell disease in Kentucky. Project activities will include developing a multilevel sickle cell education effort, establishing a system to identify and refer infants who have sickle cell disease for evaluation and treatment, and developing a coordinated system of followup and management services for patients identified with sickle cell disease or trait.

TITLE: Newborn Sickle Cell Disease Screening and Follow-up Program

PRINCIPAL INVESTIGATORS:
Susan Panny, M.D.
Judi Greenblatt, R.N., M.P.H.
Maryland Department of Health and Mental Hygiene
Division of Hereditary Disorders
201 West Preston Street
Baltimore, MD 21201

PHONE NUMBER: (301) 225–6731

PROJECT PERIOD: 10/01/88 – 09/30/90

SUMMARY:

The goal of this project is to ensure the provision of high-quality, cost-effective, comprehensive followup health care services for newborns with sickle cell disease and their families. The project will integrate three additional components into the existing newborn screening and followup program: (1) Outreach by sickle cell followup clinics; (2) an extensive educational and training campaign; and (3) a multitask centralized computer registry/data collection and retrieval system.

TITLE: New Jersey Sickle Cell Disease Project

PRINCIPAL INVESTIGATOR:
Celeste F. Andriot
New Jersey State Department of Health
Special Child Health Services
CN 364
Trenton, NJ 08625-0364

PHONE NUMBER: (609) 292–0364

PROJECT PERIOD: 10/01/88 – 09/30/90

SUMMARY:

The goal of this initiative is to reduce morbidity and mortality in New Jersey infants and children with sickle cell disease (SCD). The primary objectives are to increase the availability of comprehensive medical and psychosocial care for infants and children with SCD; to develop a system for evaluating the effects of SCD screening, followup, and comprehensive care on the health status of infants and children with SCD; and to refer all infants identified as having SCD to an SCD treatment center for evaluation and comprehensive care by 8 weeks of age.

TITLE: Oklahoma Newborn Sickle Cell and Galactosemia Screening Project

PRINCIPAL INVESTIGATOR:
Edd D. Rhoades, M.D., M.P.H.
Oklahoma State Department of Health
Division of Maternal and Child Health
1000 Northeast 10th Street
P.O. Box 53551
Oklahoma City, OK 73152

PHONE NUMBER: (405) 271–4471

PROJECT PERIOD: 10/01/89 – 09/30/90

SUMMARY:

This project proposes to address the problem of morbidity and mortality among infants with sickle cell anemia and the problem of mental retardation and possible death in infants with galactosemia. A comprehensive program of screening and followup will be implemented. Screening will be coordinated by the newborn screening coordinator and the laboratory staff, and will include education of hospital staff and primary health professionals, state-of-the-art specimen analysis and proficiency testing, systematic data entry and referral, and communication of results to appropriate health professionals and parents.

TITLE: Phenylalanine and Galactose: Automated Analysis in a Large Newborn Screening Program

PRINCIPAL INVESTIGATOR:
Kenneth A. Pass, Ph.D.
New York State Department of Health
Wadsworth Center for Laboratories and Research
Empire State Plaza
Albany, NY 12201-0509

PHONE NUMBER: (518) 453–7552

PROJECT PERIOD: 10/01/89 – 09/30/90

SUMMARY:

The goal of this project is to increase the quality and efficiency of the New York State Newborn Screening Program by updating screening methodologies, providing a mechanism for direct transfer of test results to computer data files, reducing clerical and data entry tasks, exploring a more complex data analysis system for early specimen collection, and expanding the variety of galactose metabolism disorders detectable by screening.

TITLE: Screening Impact on Services & Costs for Foster Children

PRINCIPAL INVESTIGATOR: John Landsverk, Ph.D.
Department of Sociology
San Diego State University
5178 College Avenue
San Diego, CA 92182-1900

PHONE NUMBER: (619) 594–5449

PROJECT PERIOD: 09/89 – 08/93

SUMMARY:

This research is examining the effect of providing child mental health status screening information to case management social workers in a large urban public foster care system. The aim is to ascertain how routine provision of such information affects recognition of mental health problems, referral for assessment and treatment, use of mental health services, cost of these services, and child outcomes. The study is being conducted collaboratively by researchers located at San Diego State University, the San Diego County Departments of Social Services and Mental Health, and Children's Hospital–San Diego.

TITLE: Screening Newborns for Sickle Cell Disease and Other Hemoglobinopathies

PRINCIPAL INVESTIGATOR: Peter R. Simon, M.D., M.P.H.
Rhode Island Department of Health
Division of Family Health
75 Davis Street
Providence, RI 02908

PHONE NUMBER: (401) 277–2312

PROJECT PERIOD: 10/01/88 – 09/30/90

SUMMARY:

This project seeks to prevent premature death and childhood morbidity and maximize the ability of individuals with hemoglobinopathies to develop optimally by implementing a cost-effective, universal, statewide newborn screening program. In addition to screening, the program will provide comprehensive health care services, develop multilingual patient education materials, assure access to genetic counseling services, and implement a public awareness campaign.

TITLE: Screening of Newborns for Sickle Cell Disease

PRINCIPAL INVESTIGATORS:
Lillian McMahon, M.D.
Marsha Lanes, M.S.
Trustees of Health and Hospitals of the City of Boston, Inc.
725 Massachusetts Avenue
Boston, MA 02118

PHONE NUMBER: (617) 424–5727

PROJECT PERIOD: 10/01/88 – 09/30/90

SUMMARY:

The goal of this project is to establish newborn screening for sickle cell disease in Massachusetts as a mechanism to initiate intensive comprehensive care to reduce morbidity and mortality. The program has established a system of care, treatment, and case management for infants with sickle cell disease which includes distribution of free penicillin. Additional objectives include providing education, genetic counseling, and voluntary carrier testing; and pursuing State legislation and appropriations for universal newborn screening.

TITLE: Sickle Cell Anemia: DNA for Newborn Screening Follow-up

PRINCIPAL INVESTIGATOR:
Edward R.B. McCabe, M.D., Ph.D.
Baylor College of Medicine
Institute of Molecular Genetics
Houston, TX 77030

PHONE NUMBER: (713) 799–5820

PROJECT PERIOD: 04/01/88 – 03/31/90

SUMMARY:

The objective of this study is to demonstrate the applicability of DNA techniques to newborn screening for sickle cell disease. The current practice in Texas is universal neonatal screening; small samples of blood are dried on filter paper and analyzed by protein electrophoresis. The primary aim of this project is to confirm or exclude the diagnosis of sickle cell disease by DNA genotyping directly from the original newborn screening filter paper. The purported advantages of this approach include earlier, more definitive notification of families with affected neonates.

TITLE: Statewide/Areawide Genetic Services

PRINCIPAL INVESTIGATOR: Cora L.E. Christian, M.D., M.P.H.
Virgin Islands Department of Health
P.O. Box 520
Christiansted
St. Croix, VI 00802

PHONE NUMBER: (809) 778–6567

PROJECT PERIOD: 05/01/86 – 04/30/90

SUMMARY:

The goal of this project is to identify, as early as possible, any genetic disorders within the Virgin Islands population. Specifically, the project will implement laboratory screening; training and education of nurses, laboratory personnel, and physicians; liaison relationships and linkages with community groups; and genetic testing and evaluation of newborns and pediatric age groups.

TITLE: Statewide Program for Universal Newborn Screening of Sickle Cell Anemia and Related Hemoglobinopathies

PRINCIPAL INVESTIGATOR: Jadwiga Goclowski, R.N., Ph.D.
Connecticut Department of Health Services
Family/Reproductive Health Division
150 Washington Street
Hartford, CT 06106

PHONE NUMBER: (203) 566–5601

PROJECT PERIOD: 10/01/88 – 09/30/90

SUMMARY:

The goal of this project is to decrease morbidity and mortality in infants at high risk for sickle cell anemias, related hemoglobinopathies, and traits. Through a carefully arranged plan, the Family/Reproductive Health Division, two university hematology and genetics clinics, the medical provider, and the State laboratory are involved in screening newborns and establishing an individualized plan for each sick infant for treatment, counseling, and followup.

TITLE: Texas Department of Health Newborn Screening for Sickle Hemoglobin

PRINCIPAL INVESTIGATOR: Patti Patterson, M.D.
Texas Department of Health
1100 West 49th Street
Austin, TX 78756–3199

PHONE NUMBER: (512) 458–7355

PROJECT PERIOD: 10/01/88 – 09/30/90

SUMMARY:

Since 1983, the Texas Department of Health has conducted a newborn screening program for sickle hemoglobinopathies. Program objectives include identifying newborns with significant hemoglobinopathies, ensuring followup medical treatment, providing counseling materials and guidelines to health care providers, and developing educational materials.

Cooley's Anemia, Thalassemia

TITLE: AAPCHO Thalessemia Screening and Counseling Project

PRINCIPAL INVESTIGATOR: Laurin Mayeno
Association of Asian/Pacific Community Health Organizations
310 Eighth Street, Suite 210
Oakland, CA 94607

PHONE NUMBER: (415) 272–9536

PROJECT PERIOD: 10/01/88 – 09/30/91

SUMMARY:

The goal of this project is to increase access to thalassemia screening, counseling, and education services for Southeast Asian refugee patients at Association of Asian/Pacific Community Health Organizations (AAPCHO) centers. Project activities include developing a screening protocol, developing a computerized tracking system for prevalence rates and followup, developing and implementing plans for each center, and compiling and evaluating existing materials for accuracy and cultural relevance.

TITLE: Comprehensive Care for Cooley's Anemia Thalassemia

PRINCIPAL INVESTIGATOR: Allen C. Crocker, M.D.
New England Thalassemia Program
Developmental Evaluation Clinic
300 Longwood Avenue
Boston, MA 02115

PHONE NUMBER: (617) 735–6501

PROJECT PERIOD: 07/01/88 – 06/30/91

SUMMARY:

The overall goal of the New England Thalassemia Program is to improve the quality of treatment for patients with thalassemia. Project objectives are to: (1) Disseminate information and provide community education about thalassemia, (2) identify all patients and carriers in the Region I area, (3) provide comprehensive medical care for Region I thalassemia patients, (4) provide services to promote optimal quality of life, (5) address challenges in providing services to the high-risk Southeast Asian refugee population, and (6) participate in and enhance the implementation of clinical research.

TITLE: Comprehensive Hereditary Anemia Program for Hawaii

PRINCIPAL INVESTIGATOR: Yujen E. Hsia, M.D.
University of Hawaii
J.A. Burns School of Medicine
Department of Genetics
2540 Maile Way, Box 4C
Honolulu, HI 96822

PHONE NUMBER: (808) 948–6834

PROJECT PERIOD: 10/01/89 – 09/30/92

SUMMARY:

This project aims to screen diverse Asian populations living in Hawaii for hemoglobin or glucose-6-phosphate dehydrogenase variants in order to determine how best to detect all possible combinations of these variants; estimate their gene frequencies; record their clinical manifestations; and assess the effects of early detection, genetic counseling, fetal diagnosis, and integrated health management. The program provides education to communities and physicians, written explanations accompanying diagnoses to heterozygotes, and longitudinal comprehensive care to anemia patients in cooperation with their primary physicians.

TITLE: New York State Cooley's Anemia Program

PRINCIPAL INVESTIGATOR: Peter T. Rowley, M.D.
University of Rochester School of Medicine
Division of Genetics
601 Elmwood Avenue
Rochester, NY 14642

PHONE NUMBER: (716) 275–3461

PROJECT PERIOD: 10/01/88 – 09/30/91

SUMMARY:

The purpose of this program is to provide expert medical care and counseling for affected patients and their families; to provide screening and genetic counseling for the general population in order to detect carriers; and to provide education for health professionals and the general public about this group of diseases. New York State has established four centers to provide these services, each at an outstanding medical center within the State—Cornell University Medical College–New York Hospital and Columbia Presbyterian Medical Center–Babies Hospital, both in New York City; the University of Rochester School of Medicine–Strong Memorial Hospital in Rochester, New York; and the State University of New York at Buffalo–Erie County Medical Center in Buffalo, New York.

TITLE: South Cove Thalassemia Screening and Education Program

PRINCIPAL INVESTIGATOR: Linda J. Ott, M.D.
South Cove Community Health Center
885 Washington Street
Boston, MA 92111

PHONE NUMBER: (617) 482-7555

PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

This project uses an intradepartmental, multidisciplinary approach to provide screening, case finding, and counseling services. Specific program objectives are to increase identification of patients with thalassemias through blood tests; to provide counseling, education, and support for these patients and for those at risk for trait; and to increase patient and community awareness of the disease and its control through individual and community education efforts.

Hemophilia/AIDS

TITLE: AIDS Prevention Services by Health Providers for Homeless, Runaway, and Non-School Youth

PRINCIPAL INVESTIGATOR: Oralee Wachter
ODN Productions
74 Varick Street #304
New York, NY 10013

PHONE NUMBER: (212) 432–6332

PROJECT PERIOD: 08/01/89 – 07/31/90

SUMMARY:

Hundreds of thousands of sexually active teenagers are not in school (i.e., dropouts, runaways, and homeless). They are missing AIDS education units in classrooms, and they are likely repeating behaviors which place them at risk of HIV infection and transmission. They are the hardest to reach with AIDS information and services. This project will design a new version of "Sex, Drugs, & Aids," a pioneering AIDS prevention videotape, and a new curriculum for adult health information and health services professionals.

TITLE: Assessment of Hemophilia Treatment Center Services

PRINCIPAL INVESTIGATOR: Roberta A. Olson, Ph.D.
University of Oklahoma Health Sciences Center
Department of Pediatrics
P.O. Box 26901
Oklahoma City, OK 73190

PHONE NUMBER: (405) 271–4415

PROJECT PERIOD: 08/01/89 – 07/31/90

SUMMARY:

The primary goal of this project is to gather data to determine the feasibility of integrating the comprehensive care services provided by hemophilia treatment centers (HTCs) to children with HIV infection with the services of other HIV-related health care agencies. The three major objectives of this project are to: (1) Define which pediatric patients are followed by HTCs, define the services that are provided to those patients, and determine what types of collaboration exist between HTCs and community agencies that provide services for HIV-infected children; (2) develop a process description of the structure and function of the HTCs' HIV treatment protocols/plans; and (3) determine the future plans of the HTCs for the treatment of HIV-infected children and their family members.

TITLE Boston Pediatric AIDS Project

PRINCIPAL INVESTIGATOR:
Jackie Jenkins-Scott, M.S.W.
Dimock Community Health Center
55 Dimock Street
Roxbury, MA 02119

PHONE NUMBER: (617) 442–8800 or 442–8802

PROJECT PERIOD: 08/01/88 – 07/31/91

SUMMARY:

The project unites the efforts of a coalition of nonprofit community health centers, home health care agencies, hospitals, and AIDS service organizations in the Boston metropolitan area to reach HIV-infected and high-risk women and children at the sources of entry into the health and social service system, and keep them in the system in order to: (1) Prevent further transmission of HIV, and (2) reduce the high cost of hospitalization by increasing their access to the use of lower cost community- and home-based services.

TITLE: Bronx Pediatric AIDS Consortium

PRINCIPAL INVESTIGATORS:
William Caspe, M.D.
Joanne Lukomik, M.D.
Albert Einstein College of Medicine
1300 Morris Park Avenue
Bronx, NY 10461

PHONE NUMBER: (212) 294–2497

PROJECT PERIOD: 08/01/89 – 07/31/92

SUMMARY:

The Bronx Pediatric AIDS Health Care Demonstration Project is a collaborative effort of the major health care institutions and community-based organizations which provide care to HIV-infected women, infants, and children in the borough of the Bronx. The principal participants in this consortium will combine resources in an effort to enhance the delivery of coordinated, comprehensive, case-managed health care to their constituent populations.

TITLE: Brooklyn Pediatric AIDS Demonstration Project

PRINCIPAL INVESTIGATOR: Herman Mendez, M.D.
State University of New York
Health Science Center at Brooklyn
450 Clarkson Avenue
Brooklyn, NY 11203

PHONE NUMBER: (718) 270–1828

PROJECT PERIOD: 08/01/89 – 07/31/90

SUMMARY:

The goals of this project are to: (1) Promote communication among pediatric health care and service providers and to coordinate and expand medical, educational, developmental, and social services for an increasing population of infants and children and their families with or at risk for HIV infection; (2) identify infants, children, and adolescents with or at risk for HIV infection and their families, so as to provide appropriate assessment, medical management, and access to treatment as it becomes necessary; and (3) provide case management and social services in order to stabilize and support families with or at risk from having HIV-infected children.

TITLE: Case Management Demonstration Program for Pediatric Patients and Families in Los Angeles County

PRINCIPAL INVESTIGATOR: Dale Garell, M.D.
California Children's Services
Los Angeles County Department of Health Services
2064 Marengo Street
Los Angeles, CA 90033

PHONE NUMBER: (213) 226–2405

PROJECT PERIOD: 08/01/88 – 07/31/91

SUMMARY:

The Los Angeles Pediatric AIDS Network (LAPAN) has begun to develop and implement an automated case management system for pediatric HIV/AIDS patients and their families. Through the automated system, hospital-based perinatal programs will track mothers at risk for HIV infection, and will provide ongoing followup for infants born to mothers testing positive for HIV.

TITLE:
Children's Hospital of Los Angeles
Southern California Comprehensive
Hemophilia Center

PRINCIPAL INVESTIGATOR:
Edward D. Gomperts, M.D.
Children's Hospital of Los Angeles
Division of Hematology/Oncology
4650 Sunset Boulevard, Box 54
Los Angeles, CA 90027

PHONE NUMBER: (213) 669–2339

PROJECT PERIOD: 10/01/86 – 09/30/90

SUMMARY:

The Southern California office serves as both the regional office and the coordinator for the Southern California treatment centers, with responsibility to Hawaii and the other islands. There are nine treatment centers of various sizes in Southern California. In Hawaii, hemophilia care, while provided by private physicians, is coordinated by the Hemophilia Foundation of Hawaii. Administratively, the AIDS Help and Prevention Plan (AHPP) office receives and distributes Federal funds earmarked for risk reduction activity in the region, and has historically provided the leadership and coordination of those risk reduction activities.

TITLE:
CHMC-UCSF Northern Coastal California
Hemophilia Program

PRINCIPAL INVESTIGATOR:
Joseph Addiego, Jr., M.D.
Children's Hospital Medical Center of
Northern California
Department of Hematology
747 52nd Street
Oakland, CA 94609

PHONE NUMBER: (415) 428–3372

PROJECT PERIOD: 10/01/86 – 09/30/90

SUMMARY:

The Children's Hospital Medical Center/University of California at San Francisco Northern Coastal California Hemophilia Center provides comprehensive hemophilia care and HIV-related services for all patients in a 14-county region. Major goals include continuing present services for our patients and their providers, expanding services to underserved individuals, and participating in clinical research studies to improve future care. One of the principal objectives continues to be that of serving as a resource for families and care providers who manage bleeding problems in their local health care communities. To maximize effectiveness as a regional center, education of patients, families, and community providers will remain a primary goal.

TITLE: Collaborative Study of the Effects of HIV on Development of Hemophilic Children

PRINCIPAL INVESTIGATOR: Edward D. Gomperts, M.D.
Children's Hospital of Los Angeles
4650 Sunset Boulevard
Los Angeles, CA 90027

PHONE NUMBER: (213) 660–2450

PROJECT PERIOD: 05/01/88 – 04/30/93

SUMMARY:

This project will examine a very important group of children who are infected with HIV. The patients to be studied include children with hemophilia who received repeated infusions of clotting factor concentrate derived from pooled human plasma prior to routine screening of the blood supply. A prospective longitudinal study will examine changes in neurological and neuropsychological functioning, physical growth and development, and immunological status in hemophilic children exposed to HIV and in matched control groups of HIV-negative children with hemophilia and siblings of children with hemophilia.

TITLE: Comprehensive Hemophilia Center

PRINCIPAL INVESTIGATOR: Craig Kurler, M.D.
Children's Hospital National Medical Center
Department of Hematology/Oncology
111 Michigan Avenue, N.W.
Washington, DC 20010

PHONE NUMBER: (202) 745–2140

PROJECT PERIOD: 10/01/85 – 09/30/90

SUMMARY:

This project's objectives include the development of a quarterly regional newsletter which will communicate hemophilia-related administrative, clinical, and research items of interest to the treatment center network; the development of a regionwide hemophilia and HIV patient data base; and the coordination of patient vocational counseling and rehabilitation services as well as continuing training and education for AIDS risk reduction staff.

TITLE: Comprehensive Hemophilia Center,
MCH Region IV

PRINCIPAL INVESTIGATOR: Christine A. Johnson, M.D.
Bowman Gray School of Medicine
300 South Hawthorne Road
Winston-Salem, NC 27103

PHONE NUMBER: (919) 748–4324

PROJECT PERIOD: 10/01/86 – 09/30/90

SUMMARY:

MCH Region IV has 24 individual comprehensive hemophilia programs in North Carolina, South Carolina, Georgia, Florida, Tennessee, Kentucky, Mississippi, and Louisiana. These programs provide comprehensive hemophilia care, and HIV testing, education, and counseling for individuals with hemophilia and their families. Seven of the States in the region have designated State hemophilia programs, which provide additional funding for hemophilia care.

TITLE: Comprehensive Hemophilia Diagnostic and
Treatment Center

PRINCIPAL INVESTIGATOR: Richard A. Lipton, M.D.
Long Island Jewish Medical Center
Lakeville Road
New Hyde Park, NY 11042

PHONE NUMBER: (718) 470–7380

PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

The objectives of this project are to: (1) Identify all persons with coagulation disorders in the Long Island Jewish Medical Center (LIJ) catchment area; (2) assure that quality comprehensive care is available and accessible to all identified patients; (3) educate and address the needs of patients, families, health care providers, and the community regarding the treatment and management of coagulation disorders and general comprehensive care issues; (4) manage blood resources, reduce costs, and deliver quality care in a cost-effective and equitable manner; (5) collaborate with and utilize the scientific expertise of our staff to do clinical and basic research of potential benefit to patients; and (6) implement an AIDS/HIV infection prevention program to reduce the risk and psychosocial impact of AIDS/HIV for patients, families, and providers.

TITLE: Comprehensive Hemophilia Diagnostic and Treatment Center
(Chapel Hill, NC)

PRINCIPAL INVESTIGATOR: Campbell W. McMillan, M.D.
University of North Carolina at Chapel Hill
CB #7015
433 Burnett/Womack Clinical Sciences Building
Chapel Hill, NC 27599-7015

PHONE NUMBER: (919) 966–4736

PROJECT PERIOD: 10/01/86 – 09/30/90

SUMMARY:

This project is designed to meet the following major needs: (1) Identification and enrollment of all persons with hemophilia in our catchment area (the central and eastern sections of North Carolina); (2) promotion of an optimal quality of life for all enrolled persons through multidisciplinary, comprehensive health care with an emphasis on instituting home therapy; (3) identification of all persons with hemophilia with respect to infection with HIV, including the stage of such infection (if present), associated stress, and risks of transmitting the infection to others; and (4) participation with other medical centers in the development and distribution of comprehensive health care and HIV control throughout the nine Southeastern States constituting Maternal and Child Health Region IV.

TITLE: Comprehensive Hemophilia Diagnostic and Treatment Center
(Hershey, PA)

PRINCIPAL INVESTIGATOR: M. Elaine Eyster, M.D.
Pennsylvania State University College of Medicine
Division of Hematology
Milton S. Hershey Medical Center
P.O. Box 850
Hershey, PA 17033

PHONE NUMBER: (717) 531–8399

PROJECT PERIOD: 10/01/85 – 09/30/90

SUMMARY:

The Comprehensive Care Program for Hemophiliacs focuses on: (1) Maintenance of psychosocial programs; (2) coordination and development of AIDS education/risk and family stress reduction counseling programs; and (3) promotion and integration of research activities which include NIH-funded spouse studies and clinical trials, both of which are essential for the development of effective programs for HIV prevention and therapy.

TITLE:	Comprehensive Hemophilia Diagnostic and Treatment Center (Portland, OR)
PRINCIPAL INVESTIGATOR:	Everett W. Lovrien, M.D. Oregon Health Sciences University Crippled Children's Division P.O. Box 574 Portland, OR 97207
PHONE NUMBER:	(503) 255–8716
PROJECT PERIOD:	10/01/87 – 09/30/90

SUMMARY:

The purpose of this project is to maintain a hemophilia program which will provide regionalized comprehensive care for hemophilia patients in Oregon, Washington, Alaska, and Idaho. The goals are to identify persons with hemophilia, describe their health problems, and develop a health care plan for each patient. Included in the goals are assessments of the medical, psychological, vocational, demographic, financial, social, and family impact of hemophilia.

TITLE:	Curriculum Development for Training Family Service Providers to Work with Families which Include HIV-Infected Children
PRINCIPAL INVESTIGATOR:	Elizabeth DePoy, M.S.W., Ph.D. Thomas Jefferson University College of Allied Health Sciences 130 South Ninth Street, Suite 820 Philadelphia, PA 19107
PHONE NUMBER:	(215) 928–8011
PROJECT PERIOD:	08/01/89 – 07/31/90

SUMMARY:

To meet the needs of HIV-infected children and their support systems in a culturally relevant and economically feasible manner, a community-based network of family service providers has been conceptualized. This network can only be created and maintained if the providers are trained, supervised, and assisted in their difficult jobs. This project seeks to develop, pilot-test, evaluate, and disseminate a model curriculum to educate trainers who will train family service providers.

TITLE: Dallas-Fort Worth Area Pediatric AIDS Health Care Demonstration Project–Open Arms/University of Texas Southwestern Collaborative Model Program

PRINCIPAL INVESTIGATORS: Janet Squires, M.D.
Chaplain Stefanie Held
Open Arms and the University of Texas
Southwestern Medical Center
5523 Harry Hines Boulevard
Dallas, TX 75235

PHONE NUMBER: (214) 590–2329 or 559–3946

PROJECT PERIOD: 08/01/89 – 07/31/90

SUMMARY:

The goals of this project are to: (1) Provide a family-oriented, coordinated, model program of community-based services to meet the medical, psychological, developmental, educational, basic human rights, and family unity and support needs of HIV-infected infants, children, and youth; (2) coordinate a community-based model program of case-managed support for HIV-infected women, aimed at prevention of perinatal HIV transmission; and (3) facilitate communication about educational service availability through a community-based network of agencies and groups that deliver preventive educational services to populations of youth especially at risk for contracting HIV infection.

TITLE: Development of a Statewide Health Services Network for Children with HIV Infection and Their Families

PRINCIPAL INVESTIGATOR: Barbara Kern, M.A.
New Jersey State Department of Health
Special Child Health Services
CN 364
Trenton, NJ 08625

PHONE NUMBER: (609) 292–5676

PROJECT PERIOD: 08/01/88 – 07/31/91

SUMMARY:

The New Jersey State Department of Health administers this demonstration project through its Title V program, Special Child Health Services (SCHS), to develop a statewide network of Regional Pediatric Treatment Centers in designated communities. The purpose of this network is to promote, advocate, and provide comprehensive, coordinated, family-focused services to children with HIV infection and their families. The project will link the regional centers with SCHS, which has successfully developed a statewide network of services for children requiring specialized pediatric care.

TITLE: Development of an Educational Program to Train Volunteers and Foster Families to Work with HIV-Positive Children

PRINCIPAL INVESTIGATOR:
Miriam R. Chacko, M.D.
Baylor College of Medicine
Department of Pediatrics
One Baylor Plaza
Houston, TX 77030

PHONE NUMBER: (713) 798–1905

PROJECT PERIOD: 08/01/89 – 07/31/91

SUMMARY:

The purpose of this project is to develop a recruitment and training program to improve the knowledge and skills of volunteers and foster parents caring for families with HIV-positive children. The training will prepare the volunteers and foster families to provide appropriate support services, such as respite care, assistance with access to health care, support for activities of daily living, and long- and short-term foster care.

TITLE: FACTS, Family AIDS Center for Treatment and Support

PRINCIPAL INVESTIGATOR:
Peter Simon, M.D., M.P.H.
Rhode Island Department of Health
75 Davis Street
Providence, RI 02905

PHONE NUMBER: (401) 277–2312

PROJECT PERIOD: 08/01/88 – 07/31/91

SUMMARY:

The FACTS project provides residential, in-home, and community-based care for HIV-infected children and their families. FACTS is an independent nonprofit agency chartered by the state of Rhode Island under the administrative auspices of the Rhode Island Department of Health. FACTS has formal, reciprocal working relationships with 49 community organizations to provide outreach, education, training, referral, and health and support services.

TITLE: Family AIDS Case Management Program

PRINCIPAL INVESTIGATOR: Steven Fisher
New York City Human Resources
Administration
Division of AIDS Services
330 West 34th Street, Room 311
New York, NY 10001

PHONE NUMBER: (212) 790–3163

PROJECT PERIOD: 08/01/88 – 07/31/91

SUMMARY:

This project provides ongoing case management services to support families with AIDS in Brooklyn, Upper Manhattan, and the Bronx—areas that have the Nation's highest reported levels of HIV infection in women and children. With the aim of keeping families intact, children and adults with AIDS receive assistance throughout the course of their illness, and their families receive additional support following their death.

TITLE: Great Plains Regional Comprehensive Care for Hemophilia Diagnosis

PRINCIPAL INVESTIGATOR: C. Thomas Kisker, M.D.
University of Iowa
Department of Pediatrics
2520 Colloton Pavilion
General Hospital
Iowa City, IA 52242

PHONE NUMBER: (319) 356–3422

PROJECT PERIOD: 10/01/85 – 09/30/90

SUMMARY:

This project is designed to address problems occurring at hemophilia centers in Region VII. Specifically, the project will seek to (1) persuade inactive hemophilia patients to attend annual comprehensive clinics; (2) continue to provide quality comprehensive health care services despite decreasing funds; (3) increase the knowledge of hemophilia/AIDS and improve the continuity of care; (4) ensure that all hemophilia patients have adequate supplies of treatment products; and (5) reduce the transmission of HIV. Strategies include patient followup, fundraising efforts, educational workshops, discussion of treatment alternatives, and patient counseling regarding HIV risk reduction techniques.

TITLE: Gulf States Hemophilia Diagnostic and Treatment Center

PRINCIPAL INVESTIGATOR:
W. Keith Hoots, M.D.
University of Texas Health Science Center
at Houston
University of Texas Medical School
P.O. Box 20780
Houston, TX 77225

PHONE NUMBER: (713) 792–5371

PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

The programmatic goals of the Gulf States Hemophilia Center are to: (1) Provide all appropriate facets of clinical care, including expertise in hematology, genetics, dentistry, orthopedics, and the management of complications of infection with the hepatitis or human immunodeficiency viruses; (2) educate every hemophilia patient who is infected with HIV or at risk for infection about the means for eliminating/alleviating the risk of spreading this lethal virus; and (3) foster implementation of regional strategies for improving hemophilia care and HIV risk reduction activities.

TITLE: Hemophilia Center

PRINCIPAL INVESTIGATOR:
Carol K. Kasper, M.D.
Orthopaedic Hospital
2400 South Flower Street
P.O. Box 60132
Terminal Annex
Los Angeles, CA 90007-2697

PHONE NUMBER: (213) 742–1357

PROJECT PERIOD: 10/01/86 – 09/30/90

SUMMARY:

The goals of this project are to: (1) Prevent new cases of HIV infection in sexual partners and offspring of persons with hemophilia; (2) reduce morbidity in persons with hemophilia (with emphasis on management of HIV disease, excessively frequent hemorrhaging, arthropathy, and dental disease); and (3) establish carrier status in at-risk female relatives of persons with hemophilia A and B.

TITLE:	Hemophilia Diagnostic and Treatment Centers
PRINCIPAL INVESTIGATOR:	Morris Kletzel, M.D. Arkansas Children's Hospital 800 Marshall Street Little Rock, AR 72202-3591
PHONE NUMBER:	(501) 371-9192
PROJECT PERIOD:	10/01/85 – 09/30/90

SUMMARY:

The Region VI Comprehensive Hemophilia Network is organized according to five comprehensive treatment centers (located in Dallas, Houston, Little Rock, Oklahoma City and San Antonio) and their respective satellite clinics. Identifying and serving every individual with comprehensive clinical services in Region VI is a significant logistical undertaking, upon which the necessity for HIV risk reduction counseling and education for not only the hemophilia patient, but his sexual partner(s) as well, has been superimposed. For this effort in particular, a sharing of resources and personnel between two or more of the existing hemophilia treatment centers/satellites becomes essential. Such sharing of expertise for extending the comprehensive care/risk reduction mandate also involves establishing linkages with other professional and lay organizations who share responsibility for providing similar services to other populations.

TITLE:	Model Comprehensive Health Care Program for Adolescents
PRINCIPAL INVESTIGATOR:	Karen Hein, M.D. Montefiore Medical Center Adolescent AIDS Program 111 East 210 Street (NW674) Bronx, NY 10467
PHONE NUMBER:	(212) 960–6612
PROJECT PERIOD:	08/01/89 – 07/31/90

SUMMARY:

The purpose of this project is to establish a model comprehensive health care program for adolescents ages 13–21 at high risk for or infected with HIV or AIDS in New York City. The project goals and objectives are to: (1) Develop, implement, and document a model for providing comprehensive medical and psychosocial services to adolescents at risk for or infected with HIV; (2) provide effective outreach and collaboration with existing medical and social service agencies in New York City; and (3) disseminate the model of comprehensive clinical services, and provide advocacy and technical assistance to youth-serving agencies gearing up services for high-risk or HIV-positive adolescents outside New York City.

TITLE: Model Program for Pediatric AIDS Prevention and Control in Michigan

PRINCIPAL INVESTIGATOR: George Baker, M.D.
Michigan Department of Public Health
Office of Maternal and Child Health
3423 North Logan Street
P.O. Box 30195
Lansing, MI 48909

PHONE NUMBER: (517) 335–8900

PROJECT PERIOD: 08/01/88 – 07/31/91

SUMMARY:

This project's goals are to expand the State's capability to prevent and treat perinatal AIDS. The project activities are based upon results of a 1988 statewide needs assessment by a Maternal and Infant Task Force on AIDS convened by the Michigan Department of Public Health. The task force identified three major service gaps and barriers that will be addressed by this project: (1) Lack of comprehensive outpatient treatment centers for HIV-infected women and children; (2) shortage of trained personnel; and (3) lack of effective case management.

TITLE: Mount Sinai Medical Center–Cornell University Medical Center Comprehensive Hemophilia Diagnostic and Treatment Center

PRINCIPAL INVESTIGATOR: Louis M. Aledort, M.D.
Mount Sinai Hemophilia Center
Department of Medicine
100th Street and Fifth Avenue
New York, NY 10029

PHONE NUMBER: (212) 876–8701

PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

The objectives of this project are to: (1) Identify all persons with coagulation disorders in the Mount Sinai Medical Center—Cornell University Medical Center catchment area; (2) reach out to satellite centers and Puerto Rico and assure that quality comprehensive care is available and accessible to all identified patients; (3) educate and address the needs of patients, families, health care providers, and the community regarding the treatment and management of coagulation disorders and general comprehensive care issues; (4) manage blood resources, reduce costs, and deliver quality care in a cost-effective and equitable manner; (5) collaborate with and utilize the scientific expertise of our staff to do clinical and basic research of potential benefit to the patients; and (6) implement an AIDS/HIV infection prevention program to reduce the risk and psychosocial impact of AIDS/HIV for patients, families, and providers.

TITLE: Mountain States Regional Hemophilia Center

PRINCIPAL INVESTIGATOR:
William E. Hathaway, M.D.
University of Colorado Health Sciences Center
Department of Pediatrics
4200 East Ninth Avenue, Box C222
Denver, CO 80262

PHONE NUMBER: (301) 394–8471

PROJECT PERIOD: 10/01/85 – 09/30/90

SUMMARY:

Using the multidisciplinary team approach, the Mountain States Regional Hemophilia Center Program will work toward the achievement of a series of objectives, including, but not limited to: Assessing the type and severity of hemophilia and other less frequently encountered congenital bleeding disorders; detecting inhibitors; performing periodic comprehensive evaluations; providing HIV screening, medical evaluation, and studies of immune function; teaching home (self-infusion) therapy; providing social, psychiatric, vocational, and genetic counseling; participating in investigative studies relating to hemophilia and its complications; and testing new clotting factor concentrates.

TITLE: National Hemophilia Program on AIDS Risk Reduction and Comprehensive Care

PRINCIPAL INVESTIGATOR:
Alan Brownstein, M.P.H., M.S.W.
National Hemophilia Foundation
The Soho Building
110 Greene Street, Suite 406
New York, NY 10012

PHONE NUMBER: (212) 219–8180

PROJECT PERIOD: 10/01/89 – 09/30/90

SUMMARY:

With emphasis on the national goal of preventing the further sexual and perinatal transmission of HIV, the National Hemophilia Foundation will create a National Hemophilia and AIDS Information Center and will organize its AIDS Education and Preventive Service and Comprehensive Care Services to provide risk reduction data and other data collection activities, educational programs, information dissemination, and outreach services in an integrated fashion.

TITLE: New England Area Comprehensive Hemophilia Center

PRINCIPAL INVESTIGATOR: Peter H. Levine, M.D.
Medical Center of Central Massachusetts—Memorial
119 Belmont Street
Worcester, MA 06105

PHONE NUMBER: (617) 793-6488

PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

The goal of the seven hemophilia centers in the New England region (Region I) is to provide cost effective comprehensive care to hemophiliacs and their families by coordinating regional resources and integrating already existing health services. In addition, the region will work toward achieving the national goal of preventing transmission of HIV to sexual partners and their offspring through identification of partners and education, counseling, and HIV antibody testing of hemophiliacs and their sexual partners.

TITLE: New Jersey Regional Hemophilia Program and AIDS Supplement

PRINCIPAL INVESTIGATOR: Parvin Saidi, M.D.
University of Medicine and Dentistry of New Jersey
Robert Wood Johnson Medical School
One Robert Wood Johnson Place
CN 19
New Brunswick, NJ 08901

PHONE NUMBER: (201) 937-7679

PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

The objective of this project is to continue the New Jersey Regional Hemophilia Program and expand its operation in providing high quality care to the more than 800 estimated patients in New Jersey with hemophilia and related bleeding disorders. In addition to this broad objective, we recognize and define as a separate program objective the dissemination of correct and constructive information on AIDS (including the ways to reduce the risk of transmission) and the provision of psychological support and stress management services for all of our patients and their immediate relatives and/or significant others.

TITLE: Northern Manhattan Women and Children HIV Demonstration Project

PRINCIPAL INVESTIGATOR: Zena A. Stein, M.D.
Columbia University
School of Public Health
600 West 168th Street
New York, NY 10032

PHONE NUMBER: (212) 928–5103

PROJECT PERIOD: 08/01/88 – 07/31/91

SUMMARY:

The aim of the project is to integrate the area's AIDS prevention efforts and services for the target population. Five major area hospitals have subcontracted with Columbia University to provide comprehensive services to HIV-infected and at-risk women and children in the predominantly low-income, black, and Hispanic communities of upper Manhattan.

TITLE: North Texas Comprehensive Hemophilia Center

PRINCIPAL INVESTIGATOR: George Buchanan, M.D.
University of Texas Health Science Center
at Dallas
5323 Harry Hines Boulevard
Dallas, TX 75235

PHONE NUMBER: (214) 688–3388

PROJECT PERIOD: 10/01/84 – 09/30/90

SUMMARY:

The North Texas Comprehensive Hemophilia Center was established in 1983 for the purpose of offering comprehensive diagnostic and treatment services to those children and adults with congenital blood coagulation disorders who reside in North Texas. The continued activities of the center will seek to address the multifaceted problems associated with hemophilia and its most serious complication, HIV infection. These problems will be approached through a closely linked array of clinical, educational, and research efforts carried out by skilled health care professionals who will deal with both pediatric and adult patients. Special efforts will be made to reach the underserved adult patient population.

TITLE: Oklahoma Comprehensive Hemophilia Diagnostic and Treatment Center

PRINCIPAL INVESTIGATOR: Charles L. Sexauer, M.D.
University of Oklahoma Health Sciences Center
College of Medicine
Department of Pediatrics
P.O. Box 26307
Oklahoma City, OK 73126

PHONE NUMBER: (405) 271–3661

PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

The Oklahoma Hemophilia Diagnostic and Treatment Center (OHTC) is located in Federal Region VI, which includes Texas, Oklahoma, and Arkansas. The geographic and functional area served is the State of Oklahoma, with a population of 3.3 million. OHTC is the only center in the State which provides comprehensive hemophilia care.

TITLE: Pediatric AIDS Community Demonstration Project

PRINCIPAL INVESTIGATOR: Virginia D. Floyd, M.D.
Georgia Department of Human Resources
Division of Public Health
878 Peachtree Street, N.E., Room 214
Atlanta, GA 30309

PHONE NUMBER: (404) 894–6622

PROJECT PERIOD: 08/01/88 – 07/31/91

SUMMARY:

This project is administered by the State of Georgia Division of Public Health (DPH). DPH subcontracts with four metropolitan Atlanta organizations to provide services. The project's purposes are: (1) Provide and coordinate multidisciplinary, medical, and social services to HIV-positive children and their families; (2) improve service delivery for infected children and their families by developing a community-based service network; and (3) prevent HIV infection in women, children, and adolescents through outreach and education of high-risk populations.

TITLE: Pediatric AIDS Ethical and Policy Issues

PRINCIPAL INVESTIGATOR: Ronald Bayer, Ph.D.
Columbia University
School of Public Health
600 West 168th Street, Seventh Floor
New York, NY 10016

PHONE NUMBER: (212) 305–1957

PROJECT PERIOD: 08/01/89 – 07/31/90

SUMMARY:

The Columbia University School of Public Health will organize a program to provide clinicians in pediatric AIDS projects funded by the Health Resources and Services Administration with an opportunity to examine in a systematic way the ethical and policy challenges posed by their work. At times the goal will be to underscore the ethical principles that ought to undergird clinical and public policy regarding women and children with HIV infection. On other occasions we hope to elucidate the ethical and policy complexity with which practitioners are confronted. In short, we hope to strengthen the capacity of those facing the challenges of perinatal transmission to think more clearly about the ethical context within which their work takes place.

TITLE: Puerto Rico Pediatric AIDS Demonstration Project

PRINCIPAL INVESTIGATOR: Nancy Santiago, M.D.
Puerto Rico Department of Health
Box 70184
San Juan, PR 00936

PHONE NUMBER: (809) 754–9576

PROJECT PERIOD: 08/01/88 – 07/31/91

SUMMARY:

The project objectives are to establish a multidisciplinary team to: (1) Prevent HIV transmission through outreach and culturally sensitive education; (2) provide case management to promote improved use of existing services and tracking of cases; (3) provide attendant services, transportation, and respite care to families to promote family unity and care of HIV-infected children; and (4) strengthen the professional support services in treatment sites.

TITLE: Region V East Hemophilia Treatment Center and AIDS Risk Reduction Network

PRINCIPAL INVESTIGATOR: Sally O. Crudder, R.N.
Hemophilia Foundation of Michigan
411 Huron View Boulevard, Suite 101
Ann Arbor, MI 48103

PHONE NUMBER: (313) 761–2535

PROJECT PERIOD: 10/01/83 – 09/30/90

SUMMARY:

The major regional goals of this project are to: (1) Maintain a regionalized network of comprehensive and AIDS risk reduction programs which provide comparable comprehensive care, treatment, and education; (2) coordinate the consistent collection of data from participating hemophilia treatment center programs to establish the efficiency and effectiveness of the comprehensive care model and the AIDS risk reduction effort, and (3) encourage efforts to identify other funding sources to support hemophilia treatment center and AIDS risk reduction activities.

TITLE: Region V West Hemophilia Treatment Center Network and AIDS Reduction Network

PRINCIPAL INVESTIGATOR: Janice R. Hand, R.N.
Great Lakes Hemophilia Foundation, Inc.
1725 West Wisconsin Avenue
Milwaukee, WI 53233

PHONE NUMBER: (414) 344–0772

PROJECT PERIOD: 10/01/86 – 09/30/90

SUMMARY:

The goals and objectives of this project are: (1) Maintenance of a regional network of hemophilia treatment centers which provide comparable, comprehensive care to patients and their families; (2) provision of multidisciplinary hemophilia treatment services which include, but are not limited to, diagnosis, home therapy certification and oversight, genetic counseling, psychosocial counseling, medical/financial counseling, and other forms of professional support as needed; (3) community outreach to encourage all hemophilia patients and health care providers to participate in the program; (4) reduction of the risk of transmission of the AIDS virus within the hemophilia community through intensive education and counseling; development of specialized educational approaches for preteen and adolescent patients; and provision of professional educational opportunities for center staff, other professionals, and the general community; and (5) supporting families in coping with AIDS and its impact on their lives in order to reinforce compliance with CDC guidelines regarding safer sex, appropriate infusion techniques, and the like.

TITLE: Seattle-King County Pediatric AIDS Demonstration Project

PRINCIPAL INVESTIGATOR: Kathy Carson
Seattle-King County Department of Public Health
110 Prefontaine Place, South, #500
Seattle, WA 98104

PHONE NUMBER: (206) 296–4677

PROJECT PERIOD: 08/01/88 – 07/31/91

SUMMARY:

The Seattle/King County Department of Public Health oversees this project to develop a coordinated system of comprehensive care to two groups—street youth and school dropouts engaged in high-risk intravenous drug use and/or sexual activities; and at-risk and HIV-positive women, infants, and children requiring medical/social case management services. The project builds upon existing resources with the intent of expanding the capacity to deliver services in collaboration with local agencies with specific expertise with these targeted groups. Collaboration and coordination exists through a multiagency planning committee with representatives from State and local health and social services; tertiary care facilities; educational institutions, and community-based organizations.

TITLE: South Texas Children's AIDS Center

PRINCIPAL INVESTIGATOR: John A. Mangos, M.D.
University of Texas Health Science Center at San Antonio
7703 Floyd Curl Drive
San Antonio, TX 78284-7802

PHONE NUMBER: (512) 567–5215

PROJECT PERIOD: 08/01/88 – 07/31/91

SUMMARY:

The South Texas Children's AIDS Center was created by the University of Texas Health Science Center in San Antonio, which has considerable experience in caring for HIV-infected children with hemophilia. The center has begun to build a network of health care delivery to identify and educate women and youth at risk for HIV infection, and to provide comprehensive medical care to HIV-infected families.

TITLE: South Texas Comprehensive Hemophilia Treatment Center

PRINCIPAL INVESTIGATOR: Richard T. Parmley, M.D.
University of Texas Health Science Center
at San Antonio
Department of Pediatrics
7703 Floyd Curl Drive
San Antonio, TX 78242

PHONE NUMBER: (512) 691–5265

PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

The overriding goals of the regional hemophilia program are to: (1) Maximize the quality of life for patients with hemophilia and other congenital coagulopathies; and (2) prevent the spread of HIV infection through patient and community education, while providing psychosocial support for dealing with the stress of this infection. To accomplish these goals, project objectives have been established in the areas of outpatient care, home care therapy and instruction programs, community awareness, counseling for adolescents regarding HIV infection, mechanisms for outreach to nearby communities, and coordination of center efforts with other programs addressing similar concerns.

TITLE: Strictly Confidential: Confidentiality Practice and Proposed Guidelines Regarding Newborns and Mothers

PRINCIPAL INVESTIGATOR: Charles J. Dougherty, Ph.D.
Creighton University
Center for Health Policy and Ethics
California and 24th Streets
Omaha, NE 68178

PHONE NUMBER: (402) 280–2017

PROJECT PERIOD: 08/01/89 – 07/31/90

SUMMARY:

Creighton University's Center for Health Policy and Ethics will conduct a two-year study of confidentiality in the diagnosis and care of newborns and mothers with HIV infection and AIDS. Onsite interviews will be conducted with professionals in eight major U.S. cities to determine the practical challenges of maintaining confidentiality with this patient population.

TITLE: UCD Northern Central California
Hemophilia Program

PRINCIPAL INVESTIGATOR: Charles F. Abildgaard, M.D.
UCD Medical Center at Sacramento
Department of Pediatrics
4301 X Street
Sacramento, CA 95817

PHONE NUMBER: (916) 453–2782

PROJECT PERIOD: 10/01/86 – 09/30/90

SUMMARY:

The University of California at Davis (UCD) Northern Central California Hemophilia Program provides comprehensive diagnostic and treatment services for individuals with hemophilia and von Willebrand disease who live within its catchment area. The goals of the center are to furnish the best medical treatment possible; provide education to patients, families, care providers, agencies, and center staff; cooperate with consumer organizations; and conduct research to benefit the patient population. These goals are being achieved through clinical services, cooperation and consultation, group meetings, individual contracts, mailings, telephone interviews, and videos.

TITLE: Upstate New York Regional
Comprehensive Hemophilia and AIDS Risk
Reduction Programs

PRINCIPAL INVESTIGATOR: Joyce Strazzabosco
Mary M. Gooley Hemophilia Center, Inc.
1425 Portland Avenue
Rochester, NY 14621

PHONE NUMBER: (716) 544–3630

PROJECT PERIOD: 10/01/87 – 09/30/90

SUMMARY:

The major goals of this comprehensive program are to control bleeding episodes so as to avoid the crippling effects of joint disease, and to enable patients to lead normal lives and to fulfill their potential. The objectives include the provision of annual comprehensive evaluations, replacement therapy, and psychosocial assessments, and patient education at an accessible hemophilia center, supplemented by training and placement on a home care program allowing self-infusion of prescribed blood products. The goals of the AIDS risk reduction program are to reduce the spread of infection and to reduce the stress of infected patients and their family members. The objectives include the provision of individual counseling, HIV testing, group discussions for education and support, and informational mailings.

Home Care/Alternative Care/Technology Dependent

TITLE: A Longitudinal Study of Medically Fragile Children

PRINCIPAL INVESTIGATOR: Barbara Leonard, Ph.D.
Center for Children with Chronic Illness and Disability
Box 721 UMHC
Minneapolis, MN 55455

PHONE NUMBER: (612) 626–4032

PROJECT PERIOD: 1990 – 1994

SUMMARY:

1. What are the social and emotional consequences to families who provide home care to children who are technology-dependent?
2. In families where there appears to be the capability to manage the demands of home care successfully, what factors contribute to the capability?

Based upon the Longitudinal Study of Children with Chronic Illness and Disability, the sample will include some children dependent upon medical technology. This subsample of children and their families will be followed as part of Study #1. For all of the children in Study #1, we will continue to follow them, if and when they are placed in alternative settings, examining factors that give rise to these out-of-home placements, costs associated with care in whatever setting, length of time in alternative settings, and impact of setting on child and family outcomes.

TITLE: A Study of Alternatives to Residential Treatment (ARTS)

PRINCIPAL INVESTIGATORS:
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PROJECT PERIOD: 09/27/89 – 09/28/94

SUMMARY:

The ARTS Study will be a two year longitudinal analysis of the efficacy of six community-based treatment programs [The Alaska Youth Initiative (AYI), Florida District VI Case Management Program, Kaleidoscope, Pressley Ridge Youth Development Extension (PRYDE), Ventura County Children's Demonstration Project, and Vermont's Project Wraparound] that have been identified as an innovative and exemplary alternative to traditional residential treatment settings for children and adolescents with serious emotional disorders (SED).

The study will determine if changes occur in the level of functioning of a cohort of children and their families in each of the programs during the two year follow-up period. If changes do occur, an attempt will be made to statistically associate these changes with: 1) specific characteristics of the child and/or family at the time of entry into the service program, 2) specific types of services that were received, and 3) the costs of those services.

TITLE:	A Survey of Children in Alternative Care Settings
PRINCIPAL INVESTIGATOR:	Peggy West, Ph.D. Center for Children with Chronic Illness and Disability Box 721 UMHC Minneapolis, MN 55455
PHONE NUMBER:	(612) 626–4032
PROJECT PERIOD:	1989 – 1990

SUMMARY:

1. What are the social and emotional consequences to families who provide home care to children who are technology-dependent?
2. In families where there appears to be the capability to manage the demands of home care successfully, what factors contribute to the capability?

Since this longitudinal study of medically fragile children will become an additional comparison group for the core longitudinal study, all other efforts in specifying the protocol for this project have been incorporated into the core Longitudinal Study #1.

Undertake a mailed survey of 100 non-institutional, alternative residential facilities in the state of Washington to develop a profile of which children with chronic illnesses and disabilities reside in alternative facilities. In addition, the survey will provide information on the degree to which the providers of alternative care are aware of and maintain records on the disabilities (and related needs) of their residents.

This profile, useful in its own right, will be additionally beneficial in prospectively defining one component of the longitudinal sample (Study #1). Knowing the types of disabilities more likely to be represented among children in alternative facilities, we will be able to oversample for such conditions when we enroll subjects in the Longitudinal Study and thereby capture the natural unfolding of and the factors giving rise to this placement decision.

TITLE: California Research Institute on Placement and Integration of Children with Severe Disabilities (CRI)

PRINCIPAL INVESTIGATOR: Wayne Sailor, Ph.D.
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PROJECT PERIOD: 09/01/87 – 08/31/92

SUMMARY:

The Special Education Department of San Francisco State University has entered into a cooperative agreement with the U.S. Department of Education (OSEP) to establish the California Research Institute on Placement and Integration of Children with Severe Disabilities (CRI). This five-year research program (1987–1992) surveys current definitions and placement patterns involving large representative samples of children 3–21 years old with severe disabilities. Initial data is being collected in four states and will potentially include up to eleven other states. Descriptive data is being collected on a sample of students with severe disabilities in the participating states. Extant literature has identified twenty variables, including characteristics of students, families, teachers, administrators and communities that may potentially be related to their type of placement. The descriptive data is being analyzed using a statistical model that measures the extent to which each variable affects the probability that students are placed in an integrated or segregated facility.

CRI conducts developmental research activities that stem from results of the descriptive data analysis. The research, development, and evaluation activities that are underway are geared to increase the effectiveness of special education for children with severe disabilities in integrated settings. Several waves of data are being collected longitudinally concerning predictor variables and student outcomes. Development of a structural equation model is in process to analyze these data. Results of the correlational investigations are utilized to design experimental research.

TITLE: Demonstration Project to Develop a Pediatric Service Coordination Model

PRINCIPAL INVESTIGATOR: Lyn Cooper Gill
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Department of Pediatrics
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PROJECT PERIOD: 10/01/88 – 09/30/91

SUMMARY:

The goal of this project is to enable families to provide home-centered care for their special needs children, when home is the best option, by establishing a service delivery system. This system will: (1) Promote the availability and accessibility of comprehensive quality services that address physical, psychosocial, spiritual, and developmental needs; (2) encourage continuity and coordination of care among all components of the child and family's interdisciplinary team; (3) promote communication among caregivers; and (4) be reimbursable, accountable, and responsive to change.

TITLE: Families and Communities in Transition

PRINCIPAL INVESTIGATOR: Kathy Schwaninger
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PROJECT PERIOD: 07/01/87 – 06/30/90

SUMMARY:

The purpose of this project is to encourage and expand home care as an option for families of children with special health needs. Objectives include empowering families who choose home care with the necessary skills and knowledge to become their own effective case managers; creating a collaborative system between parents and professionals in planning and caring for children; and improving and expanding both current home health and other community service provisions for children and their families.

TITLE: Families Caring for Medically Fragile Children at Home

PRINCIPAL INVESTIGATOR/
PROJECT DIRECTOR:
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Joan Patterson, Ph.D.
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PROJECT PERIOD: 1990 – 1994

SUMMARY:

An extant data set comprised of a time one survey and a two-year follow-up survey of a sample of 45 families who have a medically fragile child living at home will be analyzed. The analyses will focus on identifying: a) Unique hardships of home care which call for further support programs and policy analysis; and b) factors associated with families' ability to successfully manage these more complex care needs of technology-dependent children.

Given our intention to include a subsample of medically fragile children in the Longitudinal Study, these analyses will further inform our selection of variables to be assessed. In addition, this is a relatively new and growing population of children and there is a paucity of information on the long-term impact to children, parents, and families of providing high tech care at home. Given the presence of professionals assisting the family in providing care at home, these analyses will increase our understanding of factors associated with more effective parent-professional collaboration.

TITLE: Family-Centered, Community-Based Services for Children with Cancer

PRINCIPAL INVESTIGATOR:
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PROJECT PERIOD: 10/01/88 – 09/30/91

SUMMARY:

Traditionally, treatment of pediatric cancer has required high-technology, provider-intense care, which is expensive and disrupts family life and the child's socialization and education. The goal of this project is to design alternative means of treatment by: (1) Moving the delivery of some high-technology care for children with cancer from a Level III hospital to the community and home; (2) providing community-based intervention for those children at risk for learning disabilities caused by cancer or its treatment; and (3) developing a community-based system of followup services for long-term survivors.

TITLE: High-Tech Home Care for Children with Chronic Health Conditions

PRINCIPAL INVESTIGATOR: Juanita W. Fleming, Ph.D
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PHONE NUMBER:

PROJECT PERIOD: 10/01/89 – 09/30/91

SUMMARY:

The objective of this study is to create a data base that will aid in further describing technology-dependent children being cared for in their homes. Specific aims are to: (1) Identify selected demographic characteristics of technology-dependent children and their families; (2) define home care of technology-dependent children in terms of consumption of resources; (3) test selected hypotheses regarding the effects of the illness of these children on their families; and (4) provide the means for these data to be used by others in the development of recommendations for nursing practice relating to the care of technology-dependent children and their families. Thirteen cities in the United States will serve as areas from which data will be collected. Using structured interviews, data will be obtained from parents receiving services from private and public home health agencies.

TITLE: Intravenous Antibiotic Therapy in Cystic Fibrosis: Home Versus Hospital

PRINCIPAL INVESTIGATOR: William W. Waring, M.D.
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New Orleans, LA 70112

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PROJECT PERIOD: 05/01/87 – 10/31/90

SUMMARY:

The purpose of this study is to compare two treatment locations—hospital and hospital/home—for use of intravenous antibiotics on patients who have cystic fibrosis and who experience acute pulmonary exacerbations. The study compares the safety, efficacy, cost, and psychosocial effects of the two places of treatment.

TITLE: Model for Home and Community Care for Children Who Are Technology Assisted

PRINCIPAL INVESTIGATOR: Joanne Kaufman, R.N., M.S.
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PROJECT PERIOD: 10/01/87 – 06/30/90

SUMMARY:

This project develops a model for public/private sector collaboration in financing and case managing home care for technology-assisted children. The project also develops a methodology for educating professionals in case management for family-centered care; identifies and analyzes alternatives to hospitalization; provides family-centered case management services to over 300 Maryland children funded by Medicaid or third-party payers; and publishes monographs on family-centered case management.

TITLE: Promotion of Self-Care

PRINCIPAL INVESTIGATOR:

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PROJECT PERIOD: 1991 – 1994

SUMMARY:

1. To undertake an analysis of all tasks involved in patient management of the conditions under investigation.
2. To survey specialists, parents, and children with the condition to understand the process by which one assumes responsibility for this condition.
3. To monitor a cohort of children over time exploring the interrelationships between self-management and psychosocial factors of individual and family.
4. Develop a child flow-sheet with established norms for each of the two conditions under study which identifies by what age a child can be expected to undertake which task of condition management.

Children with chronic illnesses and disabilities have an added developmental task of learning and taking responsibility for managing their condition. In this project, clinicians, parents, and children will be surveyed to identify self-care tasks for two chronic conditions (spina bifida and cystic fibrosis) along with appropriate ages for the child assuming responsibility for each task. A sample of children will be followed to determine age norms for taking responsibility and individual, family, and community factors associated with task acquisition. These clinical benchmarks will be field-tested, with clinicians monitoring and promoting progressive self-management. The goal is to develop a clinically useful instrument which can be used by clinicians to monitor the progressive self-sufficiency of their patients with either of the two conditions under study.

TITLE: State Census of Technology-Dependent Children

PRINCIPAL INVESTIGATOR:
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PHONE NUMBER:

PROJECT PERIOD: 10/01/89 – 09/30/91

SUMMARY:

This study will be a census of all children defined as depending on extraordinary nursing services on a daily basis. Because this study will be longitudinal, we will be able to trace the prevalence of these conditions over time and look at changes within device use or in specific diseases, as well as changes in the etiologies of medical dependency. These data should be useful for program planning purposes as well as for tracking preventable causes of long-term disability.

TITLE: The Prevalence and Significance of Self-Care

PRINCIPAL INVESTIGATOR:
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PROJECT PERIOD: 09/90 – 08/91

SUMMARY:

Using data from the 1988 National Health Interview Survey (NHIS) and Child Health Supplement (CHS), this study is focusing on self-care or "latchkey" children aged 6–12 years. Self-care is defined for purposes of the research as an arrangement under which a child cares for him or herself without adult supervision for at least two hours on at least 3 of 5 school days. The study objectives are to determine: (a) prevalence of self-care among U.S. school-age children overall and by population subgroups, (b) prevalence of chronic medical and psychological conditions in children regularly in self-care, (c) number of physician visits made in the previous year by children regularly in self-care, and (d) whether there is an association between self-care status, chronic conditions, and physician use.